ABSTRACT

Title of thesis: *ACTIVE ENGAGEMENT*: DEVELOPMENT OF COOKING SKILLS FOR YOUNG ADULTS WITH AUTISM

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Autism is a broadly defined disorder of communication and social development of neurobiological origin. While adults with autism are generally invisible in the national public health surveys, increased rates of overweight and obesity among this population are apparent and few nutrition programs have been developed and evaluated for this at-risk population. The objective of the research was to test the feasibility of a community-based nutritional intervention for young adults (18– 25 years of age) with autism founded on the premise of teaching introductory cooking skills. It was hypothesized that, in doing so, it would improve their variety of diet, and enhance fruit and vegetable consumption. This nutrition intervention program was guided by Hodge et al.'s conceptual framework for developing life skills and is focused on four motivational climates that contribute to autonomy (individual production of salads), self-efficacy (competence in salad preparation skills), social-relatedness (participation in the class), and preference (consumption of the product). In sum, over the course of 25 weeks, a group of individuals were brought together weekly in a social setting and taught the necessary skills to construct individualized salads. Qualitative data was collected in the form of an

ethnography, as well as one case study demonstrating individual progression through the curriculum and the changes that occur amidst the four motivational climates. An in-depth interview with parents also provided background on eating disorders and the developmental role of food for these young adults. *Active Engagement* was found to be a feasible program for involving young adults with autism in their food preparation process, contributing to an improvement in their variety of diet, and promotion of fruit and vegetable consumption.

ACTIVE ENGAGEMENT: ENHANCING FRUIT AND VEGETABLE CONSUMPTION FOR INDIVIDUALS WITH AUTISM

by

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DEDICATION

Always and everywhere, for Conrad who gave me the inspiration, and without whom there would be nothing.

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Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction and Problem Statement

1.1: Introduction

Of late there has been a great deal of emphasis on the therapeutic value of involving individuals in food preparation and cooking as a form of nutritional intervention (1-6). Development of health promotions based on the establishment of cooking skills have focused on a number of populations including school children in home environments (2); adults with type II diabetes (3); college students living off of campus (4); overweight individuals (5); African American members of a church community (6); male senior citizens (7); at-risk youth (8); and pregnant teenagers.(9)

It is argued that including both children and adults in the preparation of their meals can enhance nutrition, variety, socialization and overall health (10-12). It is noted here that cooking is not a single activity; it is many skills combined. Moreover, cooking is a learned process that involves both physical and social components and incorporates both fine and gross motor demands as well as cognitive processing, executive functioning, memory and participation in the surrounding culture. In sum, cooking and food preparation requires "active engagement" (11), which forms the essence of the program discussed herein and provides its' name.

As public health opinion moves in the direction of cooking as a component of a healthy lifestyle, it is vital that those on the marginal ends of society and those populations at greater risk for malnutrition, obesity and chronic health conditions be included in this movement (13, 14). One population particularly susceptible to these patterns are individuals with autism. This population is believed to be at greater

nutritional risk than neurotypical[1] peers due to a variety of factors (15). First, though wholly underrepresented in national dietary surveys, smaller localized and secondary studies of individuals with autism, intellectual and developmental disabilities strongly suggest that this is a population that presents a bimodal weight distribution (16). That is, individuals with autism skew both underweight and overweight with very strong trends towards obesity (17-33). Several studies have also found higher rates of obesity for those on the autism spectrum as they progress through the life cycle into adulthood (25, 33-35). While understudied, what evidence there is suggests that obesity among individuals with autism is correlated to a number of factors including gender (25-27, 29, 31-33, 35-39), living independently/type of residence (27, 29, 38, 40-42), level of disability (25, 33), medication use (35), and physical inactivity (29, 30, 41).

Second, this population is at greater nutritional risk than the general population due to the fact that it is afflicted by high rates of eating disorders, the most pronounced of which is limited variety (43-50). Third, because of public policy initiatives, individuals with autism have been moving towards lives with increased independence during their adult years. While relocation of these individuals out of institutionalized settings is positive overall, the data has begun to depict a variance in the health status of those individuals who remain institutionalized from those living in less structured settings. This is most visibly manifested in increased rates of obesity for those with autism living with greater independence in their residential arrangements (27, 29, 38, 40-42, 51).

Finally, due to disruption in their communication skills, teens and adults with

[1] The term "Neurotypical" is meant to imply individuals with no cognitive or neurological deficits; that is, the general population. It is now used widely in scientific and research writing as well.

autism are less likely to learn cooking and nutritional skills through typical means: social osmosis, cultural traditions and mass media presentations. Consequently, *active engagement* of the type that is involved in cooking offers an immensely powerful intervention tool for individuals with disabilities in general, and autism in particular.

Chapter 2: Background and Literature Review

2.1: Autism: Definition, Diagnosis, Comorbidity

Autism is a broadly defined disorder of communication and social development of neurobiological origin (52). It is clinically heterogeneous with no clear biologic marker across the disorder (53). As a formal diagnosis it has traditionally coalesced around three basic behavioral deficits which include: restrictions in social interaction, verbal and nonverbal communication deficits and restricted range of interests and behaviors (54). Recent changes in the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual[2] (DSM-5) has altered this classification somewhat by defining a broadly inclusive label of "Autism Spectrum Disorder" (hereafter ASD) that incorporates a number of previously determined autism subtypes.[3] A diagnosis of ASD is based on deficits in social communication and interaction as well as restricted and repetitive behavior patterns.

Autism falls under the larger umbrella of Developmental Disabilities (DD), which can include deficits in cognitive and/or physical functioning and is inclusive of a number of conditions including ASD, Intellectual Disability (ID), Cerebral Palsy as well as neurogenetic, behavioral, metabolic and muscular disorders.

The percentage of individuals with ASD who have a comorbidity of Intellectual Disability (ID) is unknown and there are widely varying estimates ranging from 19.2%

[2] Used universally for psychiatric diagnoses in the United States, the DSM is published by the American Psychiatric Association and provides information regarding etiology, prevalence, age at onset, and prognosis.

[3] For a detailed explanation of the differing subgroups traditionally defined under the designation autism see Reber's *The Autism Spectrum: scientific foundations and treatment* (2012).

(55) to 75% (56) with the Centers for Disease Control and Prevention (CDC) putting the comorbidity rate at 41%. Approximately 47% of individuals with a diagnosis of ASD are believed to have average or above IQ (57). It should be noted that accessing IQ in this population can often be difficult given social and cognitive deficits that make traditional means of testing somewhat problematic (58).

Though defined as a neurological condition, autism is generally manifested as a multi-organ disorder. Autism appears to have no singular etiology, though extensive brain pathology is prevalent (59). The emerging consensus that autism is likely multifactorial in cause with no single etiological explanation (60) has led to research covering a broad range of possible biological and chemical risk factors and causative agents. Many of these are focused on *in utero* pathways, though the role of insulin in cognitive development has also been brought into greater focus of late (61, 62).

While biological and chemical agents have received most of the attention, environmental factors (such as toxins and chemical exposure) have also been proposed as a trigger mechanism (63-66). To date, there is no consensus on any single etiological factor.

Published research has addressed, but is not limited to:

- maternal deficiencies (67-71)
- deficiencies in photosynthetic vitamins (72, 73)
- pregnancy pathologies or complications (74-79)
- maternal metabolic conditions (80, 81)
- dietary fat intake during pregnancy (82)
- insulin signaling pathology (61)

- inflammation (83-85)
- deficiencies in neural stem cells differentiation (86)
- mitochondrial dysfunction (87)
- disrupted brain circuits (88)
- protein deficiencies (89)
- heavy metals (90)
- advanced maternal age (91)
- deviations in the gut microbiome (92, 93)
- epigenomic instability and fragile sites (94)

Despite the diffuse nature of research at present, very little translational application has emerged. Merging the scientific research agenda with the more immediate priorities of the various stakeholders is hindered by lack of community engagement as well as difficulty in measuring outcomes (95). Funding constraints, lack of experience in building community engagement amongst autism researchers, as well as a loss of public faith in scientific motives have also been cited as reasons for this shortage of translational approaches (95). In the coming decade this area of research should be prioritized and brought to the forefront.

The perception of autism as a spectrum related disorder reflects the fact that individuals with ASD have disabilities that range from relatively mild social impairment to more severe social disengagement typically accompanied by ID. Complicating the picture, many of the individuals on the spectrum display unique skill sets (termed

"splinter skills") that are often based on impaired cognition and accompanying diagnoses (96).

Besides ID, comorbidities are common in this population and vary widely though the most commonly reported are epilepsy (17, 41, 97-100), Sleep disorders (particularly insomnia and obstructive sleep apnea) (99, 101), motor impairment (99, 102), obesity (42, 103-109), hypertension (18, 110), high cholesterol (19), as well as gastrointestinal issues (111-113), and respiratory, food and skin allergies (41).

Females with ASD have different but equally striking comorbidity patterns when compared with males which include a number of testosterone driven conditions, such as severe acne, hirsutism, disrupted menstrual cycles, dysmenorrhea, and polycystic ovary syndrome (114). Overall, there has been an emerging understanding that the clinical manifestation of autism for females is unique from that of boys (115, 116).

2.2: Prevalence

When autism was first defined as a medical condition in 1943 (117), the prevalence rate was calculated as 4 individuals for every 10,000 (118). The Center for Disease Control and Prevention recently raised the US prevalence rate to 1 in every 68 children (57) up from 1 in 88. This number is deceptive, however, since this is a gender-influenced condition. The birth rate for boys with autism is currently situated at 1 in 42; the rate for girls is 1 in 189. Approximately 1% of the US population is believed to be on the autism spectrum. International rates of autism prevalence are comparable (119) to the United States though one study of Korean school children recorded a national rate of 2.6% (120). Rates of autism are consistent across all races, ethnic groups and

socioeconomic (52, 121, 122), and consequently affects all components of American society.

In the face of public concerns about an "epidemic" of autism (and supported by the media) an ongoing debate has emerged (123-127) as to the extent of the current prevalence of autism. Some researchers have argued that rising levels of ASD are merely reflective of diagnostic substitution (101, 123, 124, 126, 128-131), enhanced criteria, earlier age of diagnosis greater awareness of the condition, and the methodologies being utilized (124). But a 2010 review of special education services (student ages 6 to 21 years) conducted for the years 1999-2008 revealed a 349.2% increase in ASD diagnosis by special education personnel with a parallel but still reduced decline in students with intellectual disabilities (132). These figures, based on US Special Education administrative data, could not be completely offset by changes in criteria for autism though the researchers did not provide a causal explanation. This debate continues without any clear resolution at present (60).

Autism is considered a lifelong disability. There is currently no "cure" for ASD, though some individually specific interventions can affect the "trajectory" (58) of the disorder. Some scholars consider it rare for therapeutic gains to allow individuals to cease to meet diagnostic criteria for ASD (133) while others put the "recovery" rate as high as 20-25% (134, 135). For individuals with comorbid intellectual disability, long-term outcomes are usually considered poor (136). The clearest indicators for a high quality of life in adulthood are higher cognitive functioning (136-139) and language ability by 5 years of age (138, 140). Some researchers have noted IQ as stable across the lifespan for those with ASD (138), while others have noticed an improvement in

adulthood by as much as 30% (141).

Both the variability and the severity of symptoms make it almost impossible to prognosticate the progression of the condition over time (96, 102). Though the neurobiological causes of autism do not affect life expectancy, mortality rates are almost double that of the general population (142). Excess mortality is particularly pronounced for those with severe intellectual incapacity but elevated rates are demonstrated across the entire spectrum. Still, the lifespan of those with intellectual disabilities has increased greatly since the early twentieth century (143, 144) and concomitantly this population is more vulnerable to a range of chronic conditions and diseases that typically occur during the life cycle (145).

2.3: Nutritional Status of the Autism Population

The behavioral and physical manifestations of ASD provide challenges to ensuring that those with autism have adequate nutritional intake. It is long been believed, for example, that due to their selective eating behaviors (see below), the micronutrient intakes of these individuals may be minimal or inadequate (146). Other complicating risk factors include: altered growth patterns (43); an inability to meet caloric needs or an excess or dearth of energy consumption or nutrients (109, 147-158); interactions and/or interference between medications and nutrient intake or physiologic processes (159-163); metabolic disorders (164, 165); poor feeding skills (166, 167); chronic constipation (113); oral motor and swallowing difficulties (99); and reliance on enteral and/or parenteral nutrition to sustain growth (168). Typically, however, nutritional intervention is not considered for individuals with ASD unless health and welfare is considered at

immediate risk – for example, obesity (i.e., incipient diabetes) or insufficient calorie intake.

Nutritional status parameters, such as obesity, are highly obscured for adults with ASD. The Center for Disease Control and Prevention (CDC) reports that the overall rate of obesity for individuals with disabilities is 57% higher than the general population based on data collected as part of the Behavioral Risk Factor Surveillance System (BRFSS) (169). Moreover, the CDC lists obesity rates for children with disabilities as 38% higher that their typical peers. Cumulative National Health Nutrition Examination Survey (NHANES) data also suggests that obesity is significantly more prevalent among individuals with disabilities than in the general population. Disabled individuals suffering obesity were measured at 41.5%; those with extreme obesity were 9.3%. Generalized *disability* is, however, a broad term incorporating 20% of the American population and ranges from the most severe cognitive debility all the way to those individuals who have difficulty coping with the daily skills of living, such as banking.

Studies related to obesity in the ID and DD populations are more numerous and demonstrate great variability though patterns are still apparent. Data from regional samples, where height and weight were measured directly for calculation of BMI and where disabilities are specifically defined, reveal obesity rates ranging from 48%– 62% (170). Rates such as these, well above the general population, make clear that both the ID and DD populations are tremendously at-risk.

Though there are a range of national nutritional surveys available which fuel an array of research studies on the nutritional status of the general US population (as well as subpopulations), the two primary federally funded studies are NHANES and the

Behavioral Risk Factor Surveillance System (BRFSS). While neither officially excludes individuals with developmental disabilities from participating, the data collection methodology utilized in both tends to eliminate adults with autism (171).

NHANES, for example, attempts to be inclusive and highly representative of the population of the US in gathering their sample population. Due to the high amount of detailed data and information needed, however, they have "stringent reliability criteria" (172) for participation. Humphries et al. (173) attempted to recreate NHANES methodology relating to 24 hour multiple pass recall with 11 developmentally disabled adults. None of the data collected from these individuals, however, met the established criteria as set forth by the NHANES methodology guidelines. Since most adults with autism are neither institutionalized nor continually monitored (i.e. children) a proxy reporter is unlikely to be effective. Moreover, the use of proxy reporters for accurately accounting for adults with developmental disabilities has not been verified as an accurate way to collect nutritional data (172). Because of limitations such as these, it is debatable how representative national surveys are for those with developmental disabilities (34, 171, 172, 174).

In sum, while there are a variety of nationally funded nutritional and health surveys, they suffer from several limitations for those working with special needs populations generally and autism more specifically. First, the communication limitations of adults with autism prevent them from being able to meet the collection criteria of either NHANES or BRFSS. Whether cause or consequence, adults with ID and DD have been "invisible" (171) in both the large national nutrition surveys and in the resulting intervention strategies and health promotion programs. The second problem

with the nationally directed health and nutrition surveys is that little secondary research has been published that addresses the epidemiological picture for the autism subpopulation. Instead, most surveys are primarily used as comparative tools, or as material for etiological studies analyzing the causes of autism, typically from a maternal perspective (82). Because of this "cascade of disparities" (175), both Healthy People 2010[4] and the Surgeon General[5] have focused on the disabled community for future emphasis in an attempt to mediate this gap.

In 1999 the Supreme Court ruled that the adults with mental disabilities had the right to reside in the least restrictive environment possible;[6] this reflected a trend already in place to move disabled individuals (such as those with autism) into the community rather than have them placed in institutional settings. Concomitant with this greater independence has come the realization that tracking their progression into adulthood in community contexts is now more difficult.

Consequently, a consensus is emerging across many domains of autism research noting that adults with autism have been overlooked (119, 131, 176-182). Why have adults on the spectrum been ignored for so long? The fact that autism has long been the domain of child-centered developmental psychology, the collective voice of parental advocacy groups emphasizing the needs of children, reduced public empathy for adults,

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[4] The Healthy People 2020 objectives provide a long list of goals aimed an enhancing the health and welfare of those with disabilities.

[5] The publication *The 2005 Surgeon General's Call to Action: To Improve the Health and Wellness of Persons with Disabilities* lays out a program that invites both disabled individuals and health practitioners to take a more active role.

[6] In Olmstead v. L.C., the US Supreme Court ruled that individuals with mental disabilities had to right to live within the community rather than be institutionalized based on what was the least restrictive environment for the individual at hand.

and a lack of education about adults with ASD in pertinent disciplines are probably all relevant factors.(176)

2.4: Eating Patterns and Food Preferences

Food preferences are a complicated and multi-layered phenomena in all populations. Genetic and physiological components play a role in determining taste preferences (183-185) but psychological and social contributions are also significant.(186-188) Moreover, taste is also demonstrated as extremely individual and tied closely to the genetic differences in taste receptors and level of sensitivity as well as the differing constituents of saliva (189).

If food preference is multifactorial for the general population, the nature of fruit and vegetable consumption (hereafter FVC) is almost incomprehensibly complex. Government and public health recommendations continually stress increased intake of fruit and vegetables for Americans as a means of mediating obesity rates as well as mitigating a variety of chronic conditions such as diabetes, cancer, hypertension and heart disease. The World Health Organization, for example, reports that 2.8% of all deaths are related to low FVC and list it as among the top 10 risk factors for global mortality (190). The *Dietary Guidelines for Americans 2010* have made increased FVC a national priority, stressing that nutrient dense foods such as fruits and vegetables are needed to replace the preponderance of energy dense foods in the modern diet. Moreover, the Dietary Guidelines also emphasize the fact that all cultures without epidemic obesity emphasize FVC (191).

Though increased FVC is encouraged across all demographic groups,

understanding influences on this behavior are embedded in a variety of mediators as well as confounding factors. What influences contribute to or deter increased consumption of fruits and vegetables? Cross-sectional research demonstrates the powerful influence of preference (192), availability and accessibility (192), sensory appeal, habit, health status, social context, cost, availability, ease of access, personal mindsets, and mass media messages (193).

2.4.1: Eating Pathologies in the Autism Population

Understanding eating patterns in general, and FVC in particular, is complicated in the context of autism due to the fact that individuals on the spectrum suffer from a variety of disrupted eating patterns (157). Pathologies in eating behaviors are reported as high as 90% among children with ASD (46, 48, 194). For those with ID and DD, 97% (195) have been found to have at least one eating problem. Despite the fact that eating disorders are so widespread amongst this population, they are not considered a diagnostic criteria (167).

Issues reported are very diverse but can be broadly categorized. Self-limiting diets, for example, are manifested in feeding difficulties (43, 196), highly selective preferences (157, 197), food refusal (43), or limited variety (43-50). Sensory issues predominate in this population and are often represented in specificity in presentation (198) and texture (194, 199, 200). Pharmacological and biologically-based eating disorders are also represented amongst this population and include pica (157, 197, 201) and psychogenic vomiting (16). Lastly, challenging behaviors that typically present in autism are manifested via compulsive grazing (202) or disruptive mealtime behaviors (199, 203).

Thus, sensory processing issues (199), medical conditions (204), pharmacology and physical issues, such as oral motor development all contribute to the universe of autistic eating pathologies. Whatever the underlying cause (204), the effect of eating disorders on mental, physical, social and overall health status remains murky (16) and what little is known is focused exclusively on children with ASD. In any case, the highly variable nature of these eating disorders implies that they are multifactorial in cause and treatment options will have to reflect this complex etiology (205).

Matson et al. (205), for example, was able to define a relationship between food refusal and social skills deficits in individuals with ID. Specifically, those with ID and food refusal behaviors also experienced a lack of social skills manifested as challenging behavior disturbances. The significance of this study is the fact that it embeds a particular eating pathology within the social domain and acknowledges that any attempt to target an intervention for this behavior will require an emphasis on social aptitude.

While food pathologies are personal and unique for each individual on the spectrum, they are not random: Individuals with autism overwhelmingly prefer energy dense foods to nutrient rich foods. It should be noted that no relationship between food selectivity and degree of severity of autism has been discovered (47). That is, food preferences appear to influence food selection more than the diagnostic characteristics of autism.

2.4.2: The Manifestation of Eating Disorders on Nutritional Status

Despite a significant body of research addressing eating pathologies among the autism population, there are conflicting interpretations as to how these behaviors affect the overall nutritional status for those with autism (147, 153, 156, 167, 196, 198, 206-

210). For example, an analysis of intake and nutritional status for 15 children (ages 2-4) with ASD undertaken by the University of Pittsburgh (153) found an increase of eating problems when compared with a typically developing control group. Noted pathologies included disruptive mealtime behaviors as well as food specificity and food refusal. Despite this, the authors concluded that nutrient intake (via food recalls and diaries completed by parents/guardians) was comparable in all macro and micronutrients with the exception of magnesium, where the *control group* was found to be deficient in intake. A great deal of variability was noted within both groups, however.

Another investigation analyzed data from the Avon Longitudinal Study of Parents and Children[7] (ALSPAC) at specific age markers. Utilizing a specially constructed food variety score, the content of the diet for a cohort with autism was analyzed (average age 45 months at diagnosis). While this group was found to have less varied diet than the typically developing controls, they also consumed far less sugary drinks. No difference was determined from the control group in weight, height or BMI at the 18month and 7 year markers and growth was not found to be impaired. Other studies (147, 153, 211, 212) have concurred that macronutrient intake of children with autism does not appear to differ significantly from typically developing children.

Other studies, however, have reached different conclusions. An analysis of 22 children with ASD (49) (average age 8.2) contrasted eating patterns with a typically developing cohort for food variety. Diet variation was found to be significantly more limited among the children with ASD and selective eaters were also more likely than typical controls to be at serious risk for at least one nutrient deficiency. A range of

[7] Run by the University of Bristol, ALSPAC is a cohort study of children born in Avon, England during the years 1991 and 1992.

research has also concluded that children with autism were deficient in differing nutrients including folic acid (109, 151), niacin (151, 213), vitamin A (151, 206), vitamin B6 (213), vitamin C (151), vitamin D (206, 214), vitamin K (153, 214), iron (151, 153, 213)), zinc (109, 213), and calcium (151, 153, 206, 213-215). In the final analysis, examination of dietary intake for children with autism yields conflicting results.

Even less is known about dietary intake for adults with ASD. Fodstad and Matson (167) compared a group of 60 adults ranging from 18 to 69 years old with dual diagnoses of ID and ASD to a group with only ID labels utilizing the Screening Tool of fEeding Problems (STEP).[8] The authors found that those individuals with ASD and ID diagnoses had more difficulties with feeding skills than individuals with only an ID diagnosis. Areas of direct interest studied included Aspiration Risk, Selectivity, Feeding Skills, Refusal Related Behavior Problems, and Nutrition Related Behavior Problems. The authors concluded that those with ASD and ID suffered from more issues related to food refusal; those with ID primarily experienced more problems related to level of feeding skill. The difference between the two groups in terms of selectivity were not considered significant and it was hypothesized by the authors that the more narrow range of food preferences experienced by those with ASD was due to the preference for routines and sameness that marks autism in general. There were no findings relating eating disorders with nutritional status.

Gravestock (16) analyzed the range of eating disorders for adults with ID with a

[8] STEP The Screening Tool of fEeding Problems (STEP) is a 23-item instrument created to screen for a number of feeding and mealtime behavior problems that are typically seen in individuals with intellectual disabilities. Its' applicability for low-functioning autistics is presumed given that ID is highly comorbid.

literature review that assessed weight analysis, psychopathology studies, and eating disorder research for this population. Of paramount importance, he found wildly differing rates for numerous aspects of this population across 8 different studies. For example, underweight individuals were found to vary from as low as 5% to as high at 45%. Institutionalization rates ranged from 3% to 42% and diagnosable eating disorders ranged from 1% to 19% of those studied. Overweight among those with ID ranged from as low as 2% to as high as 35% with obesity running the gamut from 10% to 43%. The wide range of results across 8 different surveys effectively demonstrates the difficulty in determining the overall nutritional status of this population.

2.4.3: Tools utilized to assess eating problems

Part of the difficulty in addressing the important issues related to eating pathologies and nutritional status for those on the spectrum is the dearth of appropriate assessment tools. The Screening Tool of fEeding Problems (STEP), introduced above, was devised for the assessment of adults with Intellectual Disability (ID) and was intended to provide a systematic and relatively simple mechanism for identifying eating pathologies (216). The percentage of individuals with ASD who have a comorbidity of ID is unknown and there are widely varying estimates ranging from 19.2% (55) to 75% (56). Due to a widening of criteria for all autism-related disorders, it is thought that the current comorbidity rate is somewhere between 40%-55% (98, 102, 217). These figures, however, are cross-sectional and most practitioners work in phenotypic pockets rather than across the breadth of the autism spectrum. For those that work with low-functioning individuals on the spectrum, the ID rate is most likely closer to 100%. Consequently, for these individuals with autism, STEP may be an appropriate screening tool to assess

pathologies of eating.

A variety of other specially adapted food frequency and mealtime behavior questionnaires have been developed but are exclusively focused on children on the spectrum. The Children's Eating Behavior Inventory-Revised (CEBI-R), the Behavioral Pediatric Feeding Assessment Scale (BPFAS), and the Brief Autism Mealtime Behavior Inventory (BAMBI) have all been administered to this population(218) though on very small sample populations and with a pediatric focus (44, 218).

To date, nutrition professionals have not yet validated an effective or appropriate method for straightforward dietary intake assessment of independent adults with ID and DD. Problems to overcome in this process relate to collecting accurate and valid data given the structural problems for this population with memory, comprehension, fine motor, literacy, and communication (172). Recalling past events, estimation and recording are all extremely advanced skills that are outside the realm of possibility for most adults with autism or more generalized intellectual disabilities. Consequently, those individuals who have been studied tend to be those that are institutionalized (and hence can be monitored closely) or those who live in contexts where their behavior can be closely scrutinized. For these reasons much more is known about the nutritional patterns of children and adults that live with strong support systems.

2.5: The Transition into Adulthood on the Spectrum

One of the most curious aspects of the transition to adulthood for this population is the fact that individuals on the spectrum with normal IQ ranges seem to experience a mild cognitive decline as the leave behind the educational setting (219, 220). This is

hypothesized to be a reaction to the reduced stimulation in the period following formal schooling (139). On the other hand, it is generally asserted that symptoms typically related to lower functioning individuals on the spectrum tend to abate in severity by early adulthood (139, 140, 221-224). These modest changes, related to behavior as well as verbal and nonverbal communication, include alterations in rote patterns of repetition and restriction and "maladaptive behaviors" (223) are often decreased as are the fixation on special interests (225).

Language and nonverbal skills are seen to modestly advance during early adulthood (222, 223). However, social behavior as manifested in reciprocal interaction does not appear to be greatly affected by the transition to adulthood (224) and remains a set part of the phenotype into adulthood. Lastly, the pronounced difference between verbal and nonverbal IQ scores that distinguishes this population is mitigated modestly (138) in adulthood, thus contributing to the notion that during this transition period a minor shift is occurring.

Why there would be a reduction or change in behavior is incompletely understood but is hypothesized to be related to restructuring of gray and white matter in the brain during childhood and into adolescence (225), to a reduction in sensory pathologies as part of the natural aging process (119), greater self-awareness (226), or the development of the ability to draw on learned skills. Parents of children with ASD have also noted these changes anecdotally as occurring in the transition from adolescence into adulthood (139).

2.6: Nutritional Intervention in the Autism Population

Based on the widespread presence of eating disorders within this community,

nutritional interventions for individuals with autism have attempted to enhance both FVC and overall increased variety. Table 2-1 presents the summary of published nutritional intervention studies for the population with ASD and DD. Strategies utilized for such programs have been diverse and have included visual tools (utilizing a plate model) (227), behavior modification (50, 228), and individually reinforcement with hierarchical exposure (229). Differential reinforcement of alternative behaviors (230) was included as was escape extinction, whereby a behavior, once rewarded, is no longer favored. Taste exposure, and fading of prompts (231), as well as functional analysis (or operant conditioning) (232), re-presentation (233), and altering of foods with preferred flavors (flavor-flavor conditioning) (234) were also built into programs. Direct modification of less preferred foods with condiments was also utilized (228). Educational programs addressed staff/caregiver education and training (235), and more direct nutritional education for those with autism (236).

There have also been a number of health promotions designed for those with ID and DD that have typically addressed self-efficacy, nutritional knowledge and reduction of BMI (13, 237-245). While research and interest in autism is at an all time high, the predominant focus remains on children with autism, primarily because most treatment strategies emphasize early intervention in the belief that it will enhance the long-term prognosis (246). Moreover, those programs that do address adults on the spectrum – such as the handful of nutritional interventions and health promotions discussed here -- typically sample high functioning individuals. This is likely due to the need to adequately measure outcomes and the fact that those individuals without significant handicaps can more actively participate in the measurement process (247).

There is a dearth of adequate programs for lower functioning adults on the spectrum as well as an emerging picture of a population that is at risk for obesity and the chronic conditions that typically accompany it. *Active Engagement* was designed to address this undeserved and at-risk population as well as fill the gaps and tackles issues of concern not otherwise considered in existing programs. First, *Active Engagement* is specifically designed for adults with ASD. With the exception of one existing program that included individuals with DD up to the age of 21 (235), all of previous nutritional interventions for this population were designed for children and adolescents. Second, *Active Engagement* puts individuals in the central position of determining how and what they will produce and consume due to an emphasis on choice and decision-making, referencing the concept of self-autonomy. Existing interventions for individuals with ASD/DD/ID, such as those described herein, are intended only to mitigate eating disorders through behavior modification, masking, or representation.

Third, the nature of data collection in *Active Engagement* (discussed below) and the subsequent qualitative analysis allows for observed behavior utilized and interpreted as a form of communication. In this way, non- and minimally verbal participants are provided with a voice, a means to express attitudes about both food and preference.

While previous nutritional interventions have not specifically addressed cooking skills, more generalized ASD curriculum have encouraged the development of competencies that are generally termed life skills (14, 248-253). Life skills are an undefined set of talents that are taught to assist challenged individuals with the management of their lives and to encourage as least restrictive environment as possible for their adult futures. For some in the special needs community, these are skills that

must be learned in a direct educational environment because their psychosocial disabilities do not allow them to acquire such abilities in a generalized way (that is through trial and error in daily life). Life skills curriculums are widespread but vary greatly; cooking is a component of most (See Table 2-2).

Programs focused on the teaching of dedicated cooking skills and techniques for those with autism, ID, or DD have incorporated differing objectives. These include packing a lunch (254), preparing a snack (255), using pictorial self-management to create a lunch menu (256), food preparation via video modeling (249, 252), virtual kitchen instruction (257), and training through color-coded food photographs (258).

Of late there has been increasing interest in the use of technology across many subject matters for this population (248), particularly the iPad and other electronic tablets for transforming teaching methods for those with autism and other disabilities (259-263). The power of such mobile devices stems from the fact that they can combine two methods into one: video (modeling, self-modeling, prompting and subjective point of view) with the convenience of a hand-held computer device. Though the potential of these approaches is clearly significant, they are not currently in widespread use.

Table 2-1: Nutritional Interventions in the Autism/ID/DD Population

Author(s), year	Target Population, N	Goals/Purpose	Intervention Venue	Intervention Strategy	Evaluation Instruments	Outcomes
Wallen EF, Mullerdorf M, 2013	16-21 years old students with ID n = 89	To evaluate a multifactorial intervention to determine if "plate model" will result in healthful food choices	School cafeteria dining facilities	Plate visual used to encourage FVC	Measurement of Visual plate	88% of the both control and intervention groups filled their plate with greater than or equal to 37.5% of vegetables on four separate occasions of measurement
Ahearn WH., 2003	14 years old boy n = 1	To determine if use of condiments would lead to enhanced vegetable consumption	Clinical setting	Antecedent-based strategy: Adding condiments to previously rejected vegetables.	Counting of bites with multiple observers for accuracy.	Addition of a preferred condiment positively altered the probability of acceptance.
Koegel R., et al. 2012	Children (6.4-7.8 year old) n = 3	To determine if individualized reinforcement and hierarchical exposure of preferred re-enforcers will increase flexibility	Clinical setting	Use of range of re-enforcers chosen specifically by the participants; most desirable used to increase food flexibility.	Videotapes of sessions were reviewed by multiple observers to code for consumption of new foods.	All participants expanded their food repertoire and spontaneously requested new foods during follow up/generalization.
Girolami PA, et al. 2007	4 year old boy n=1	To assess treatment of expulsions for child with selectivity	Clinical setting	Re-presentation of expelled bites to address food selectivity	Foods were presented both with a brush and spoon. Acceptance/ expulsion measured.	Fewer expulsions observed with brush.
Mueller MM, et al. 2004	3-4 years old n = 2	To analyze antecedent variables in feeding: Presentation of non-preferred foods before blending and after to increase consumption.	Clinical setting	consequence-based intervention	Computers used to collect frequency data on acceptance and mouth clean. Converted to per-centage of trials for acceptance and mouth clean. Multiple observers	Consumption high for non-preferred foods that had been blended; low for non-preferred foods that had not been blended. Variety of foods consumed by the participants increased

					calculated.	from one to 16.
Gephart EF, Loman DG 2013	5-21 years old youth n =65	Program implemented a variety of methods to support weight management strategies among individuals with DD. Caregiver staff provided with weight management education, communication tool for youth weight indices, weight & physical activity goals, dietary orders, and monthly follow-up communication	Community group homes	Implementation of strategies for weight management	Changes in youth growth indices Nutritional and physical activity practices Interview tool with staff	Significant decrease in mean body mass index percentile ($p<.01$) though primarily from change in the healthy weight category. More than 80% of the 40 youth achieved their weight goal. A significant improvement in daily fruit (($p = .001$) and vegetable consumption $p < .001$) reported.
Laud RB., et al., 2009	1.5- 12 years children n = 46	To evaluate the short- and long-term effects of behavioral treatments on feeding issues	Clinical setting	Behavior therapy 3 hours a day and oral motor therapy 1 hour a day, 5 days a week	Visual observation and measurement of bite acceptance, refusal behaviors, negative vocalizations, grams consumed and oral intake Childrens Eating Behavior Index (CEBI) Caregivers Satisfaction Survey	Acceptance ($p < .000$), refusal behaviors $p < .007$), and grams consumed ($p < .000$) increased significantly while negative vocalizations significantly decreased ($p < .000$) from admission to discharge.
Valdimarsdottir et al., 2010	5 year old boy n = 1	To investigate use of Applied Behavior Analysis (ABA) in mitigating eating disorders in children with autism	2 settings at preschool	Applied Behavior Analysis: application of operant and classical condition in pursuit of a modification of behavior	Observers recorded the type and number of bites of non-preferred food. Team members also counted bites	Differential rein-forcement of alternative behavior, non-removal of the fork, and stimulus fading increased consumption of non-preferred food
Najdowski, et	6 children (5 with autism	To determine the use of parents as therapists for	Home based	Functional analysis using a multi-	Scoring of behaviors related to food	Parents can be effectively be trained to

al., 2008	and food selectivity)	experimental functional analyses of inappropriate mealtime behavior	environment	element design. Method employs principles derived from behavior analysis to determine the motivation for a behavior; incorporates behavior, antecedents and consequences.	acceptance, refusal, food expulsion, etc. Parents taught protocol and how to follow up	implement prescribed treatment related to eating behaviors
Seiverling, L. et al., 2012	Parents of 3 children with autism	To train home based treatment of taste exposure, escape extinction (reward of a previous behavior is halted), and fading (prompting gradually withdrawn)	Home based environment	Behavioral skills training: taste exposure, escape extinction, and fading	children's acceptance of bites and disruptive behavior	Increased acceptance of new foods; less disruptive behaviors; gains maintained at follow-up

Table 2-2 Life Skills Programs Directed Towards Autism

Author(s)	Target Population	Goals/Purpose	Intervention Venue	Intervention Strategy	Evaluation Instruments	Outcomes
McGraw-Hunter, M., et al. 2006	Individuals with traumatic brain injury n = 4	Systematic Instruction: Retraining of cooking skills	Participant's home kitchen	Video self-modeling and feedback	Observer and secondary observer agreement	3 of 4 participants reached acceptable performance level in 4 sessions
Mechling, L. C., et al. 2013	males with ASD in high school n = 4	To determine whether commercially available or custom made video prompting program was most effective in directed completion of cooking project	home living room of the high school	Comparative study of video prompts	Observer and secondary observer agreement	Procedure with custom-made video prompts was found to be most effective
Mechling, L. C., et al. 2008	Young adults with moderate ID n = 3	Assessment of video modeling for instruction in teaching independent performance of multistep tasks in cooking	Kitchen of the apartment rented by the school system for delivering home living instruction	Video prompts used to present multiple modes of information including auditory, visual, and animated cues	Multiple Probe Research Design	Variable results for participants, though generally demonstrated a higher percentage of independent correct responses for assigned tasks when using the portable DVD player and required a low number of sessions to achieve criteria
Taber-Doughty, T., et al. 2011	Teenagers with mild ID n = 3	Assessment of use of video prompting and modeling to teach simple cooking recipes	Classroom kitchen	Alternating treatment design with a pillow-up and withdrawal probe	Baseline data prior to intervention. 2 observers noted number of steps participants could complete with video support. Informal interviews of participants	All three individuals showed marked increase in cooking independence. Video modeling more effective for two students and video prompting more effective for the third

Chapter 3: Research Objectives, Aims and Hypotheses

According to the World Health Organization (264), a health promotion is a "process of enabling people to increase control over and improve their health." In a population with intense food selectivity and which skews away from healthy body weights, a health promotion that involves this population in food preparation is situated as a powerful intervention strategy.

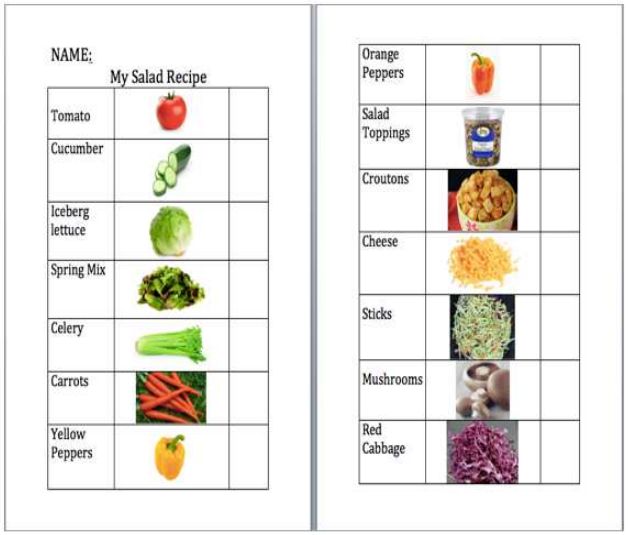
At the outset of *Active Engagement*, the central guiding intention posed by the researcher was the identification and development of methods and tools needed to develop a health promotion for young adults with autism that would invest them in their own food preparation process. Such a mission, deliberately broad and inductive in nature, was addressed with a qualitative research design derived from ethnography and the use of participant observation (265).

The substance of the data reflects an ethnographic collection of the accounts of individuals who moved through the course -- the process. Included as well is a metaphorical tool kit, the supporting materials, adaptive tools, technology, activities and approaches needed to ensure that individuals with autism are able to participate in the basic components of the program – the output, or product.

Supporting materials to be collected during the research process included items such as:

- adapted tools (i.e., knives, peelers, graters, food poppers, etc.) to prevent accidents, address motor difficulties, and allow for increased participant independence

- illustrated collection of possible ingredients. "My Salad Recipe" (Figure 3-1) provides participants a visual inventory and serves as the basis for creating a personal salad recipe.



- illustrated map of food textures. "Carrots" (Figure 3-2) food map allows participants a visual inventory of possible texture options. Participants are encouraged to try different texture modalities that require the ability to utilize new and different tools.

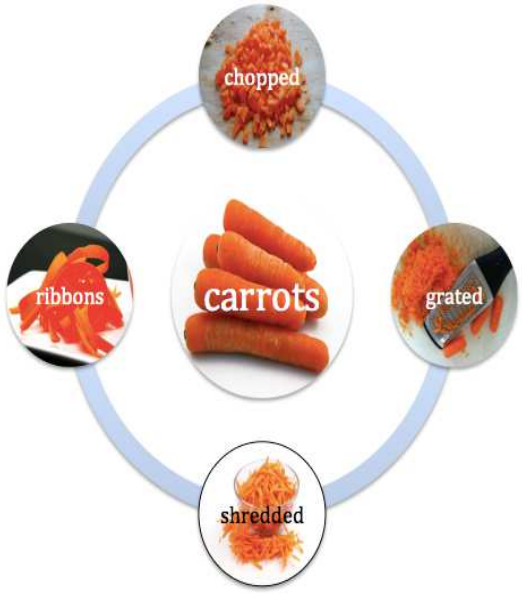


Figure 3.2: Carrot Food Map

- specialized procedures: i.e. songs/chants to teach hand motion or processing skills
- specialized mats to ensure knife stability
- social promotion activities: name song to acknowledge everyone in the group as well as the class routines.

3.1: Aims and Hypotheses

Active Engagement was built with the following aims/hypotheses:

Aim 1: To explore the feasibility of health promotion program based on the development of cooking skills for young adults with autism. This aim is based on the understanding that the development of cooking skills contributes to the enhancement of dietary quality and variety. Moreover, the course was designed so as to be embedded into a specific context that allowed systematic access to fruits and vegetables with the expectation that repeated exposure in a supportive environment would contribute to preference.

Hypothesis 1-1: that the development of cooking skills among young adults with autism will greatly contribute to a change in health related behaviors.

Aim 2: To develop the skills necessary for cooking as a collective learning process (autonomy, self-efficacy, preference and social-relatedness) among young adults with autism.

Hypothesis 2-1: When autonomy, self-efficacy, preference and social-relatedness are optimized, the ability to acquire food preparation skills will be optimized for this population.

Aim 3: To give voice to those with autism who, because of communication deficits, cannot participate in research via traditional methods such as interviews or surveys.

Hypothesis 3-1: Using an ethnographic approach, case studies and qualitative analysis will provide a mechanism for the privileging of voices for those with severe communication disorders.

Chapter 4: Methodology

4.1: Study Setting/Sample Selection:

Community Support Services (CSS) agreed to host the *Active Engagement* in September, 2013 and provided all of the necessary materials, including support staff, classroom facilities, foodstuffs, technology, printed materials, and participants, along with accompanying aides. All CSS clients who participated had IRB-approved letters of consent on file signed by a caregiver or guardian.

CSS, a 501 (c)(3) non-profit charitable organization based in Gaithersburg, MD, offers a wide range of residential and day services for individuals (children to adult) with autism and other developmental disabilities. Working with a variety of state and local government agencies, local businesses, and other human services providers, CSS provides a full range of therapeutic and vocational opportunities to this underserved population and is one of the largest service organizations of this type in the metropolitan region.

The sample population for *Active Engagement* consisted of young men and women who were clients at CSS, whether in the school or vocational program. The CSS Director of Adult Day Services and Director of Therapeutic and Individual Services were responsible for determining who would participate in *Active Engagement* based upon inclusion and exclusion criteria established by the researcher:

4.1.1: Inclusion Criteria

Based upon the conceptual framework and program design, the researcher designated the following inclusion criteria for the study. Participants would:

1) have physician-diagnosed autism or related developmental or intellectual disability;[9]

2) belong to the age cohort between 18 to 25 years of age;

3) have adequate muscular control to participate in fine and gross motor tasks;

4) be able to self-feed with minimal assistance;

5) attend the class with a dedicated aide to ensure that challenging behaviors were dealt with according to the individual's behavior plan;

6) be able to participate on a regular basis given the class day and time.

4.1.2: Exclusion Criteria

As determined by the researcher based on the program design, exclusion criteria were also determined. Participants would not:

1) have dietary restrictions that would prevent them from consuming basic salads;

2) have challenging behaviors that would excessively distract or interfere with class benefits for other participants.

It was understood by CSS Staff that the intervention was intended to enhance overall dietary variability and nutritional status and those individuals who were in particular need of this type of assistance gained special attention for inclusion by the CSS Staff.

4.2: Sample Size

Over the course progression of *Active Engagement,* approximately 30 individuals

[9] These could include, but were not limited to, cerebral palsy, epilepsy, and Down Syndrome.

participated either regularly or sporadically in class activities; however not all of these young adults were officially part of the ongoing research study. Official data collection addressed 13 individuals who came from two separate classes composed of seven to nine individuals of mixed genders. While the primary intervention component was class-based education, five individuals had one-on-one or dyad instruction, using the same course protocol.

One-one one instruction was required when challenging behaviors were sufficiently serious as to limit access to other individuals. In those cases, individual instruction proceeded outside of the group class with the same materials and comparable goals. Though the opportunities for social interaction were altered, the issues of autonomy, self-efficacy and preference remained in play.

This variation on *Active Engagement* is viable in situations where interaction with peers would hinder the process rather than enhance it. For example, individuals with profound eating disorders (such as pica), or individuals who are aggressive with others might be better served in one-on-one settings where their needs do not interfere with the other course participants. This is also an appropriate strategy for participants who, for logistical or physical reasons, could not attend the scheduled class though it was determined that they would benefit from continuing the class on an individual basis.

4.3: Protection of Human Subjects

The *Active Engagement* protocol was approved by the Institutional Review Board (IRB) at the University of Maryland at College Park. All participants had consent provided by a parent/guardian. No participant was excluded based upon race, ethnicity or

religion.

No major risks were anticipated for participants in this study as plastic adapted knives were utilized. Though there was a risk that participants might become frustrated or upset by attempting a challenging activity, this was mitigated by allowing the individual's aide to end the session or take the individual out of the room, based on the aide's judgment and discretion.

Individuals were allowed to leave the classroom for other reasons if their aides agreed that it was appropriate. Participation in the activities of the class were all voluntary and there was no coercion to participate or to consume the final product (salad) that was produced. They gained from contributing to the existing knowledge base and received the therapeutic benefit from developing new skills and enhancing their food preferences.

Confidentiality was maintained for the subjects by changing their names to non-identifying names for the purpose of written analysis. This procedure was used in all written records. Only the researcher, advisor and CSS personnel had access to the actual names of the participants and the video, digital or pictures taken during the research process. Pseudonyms were used to protect the names of participants in video, digital or pictures. All identifiable data (names, video, digital or pictures) will remain in a locked cabinet in the researchers office and will be destroyed 5 years after completion of the data analysis.

For reports or articles about this research project, identity will be protected to the maximum extent possible. Information may be shared with representatives of the

University of Maryland, College Park or governmental authorities if any individual is in danger or if required to do so by law.

4.4: Evidence Based Practices in Autism

Evidence-based analysis is set as the goal in all empirical fields, including nutrition. It remains the objective for those working within the autism population as well, but methodological approaches to establish such standards remain frustratingly elusive (266). Many interventions – some widely practiced within the autism community – lack empirical evidence of efficacy (267). After all, to achieve this standard a program must be organized around components that can be measured. In the context of individuals with autism, this has often meant measuring discrete aspects of behavior rather than "meaningful and long-term behavior change" (266). Moreover, it has also meant that sample populations are often drawn from higher-functioning phenotypic pockets rather than lower-functioning individuals with communication deficits.

Reviews of the major educational programs for this population have concluded that it is very difficult to create a single manual to define how a program should proceed. It is noted that "the population of people with autism is too heterogeneous and comprehensive autism intervention programs are too complex for an *overall program* manual to be either practical or informative"[emphasis in original] (266).

Because of issues such as this, the researcher consciously chose to create a toolkit, rather than a program manual for implementation of *Active Engagement.* After all, consumption patterns and food behaviors are not discrete behaviors. Food and all of its' related practices are situated at the intersection of culture, access, self-autonomy, self-

efficacy, and social mores. Moreover, there is no universal understanding of what constitutes the most precise and effective means for teaching those on the spectrum. The movement at present, in acknowledgement of the immense diversity within the condition, is towards an understanding that there needs to be a greater emphasis on individuals and their strengths and deficits, including how symptoms present, IQ, social ability and interest, and level of involvement (131, 268-271). Nevertheless, there are "maximally effective methods" that should provide the framework when attempting to intervene with this population (266, 272).

Active Engagement is situated as a blending of nutrition research with anthropological methods of evaluation. Here anthropology serves as a bridge between social theory and practical policy (273). The lens of culture that is the essence of Anthropology as a social science has previously addressed public health issues by contributing intervention designs, project evaluations and policy critiques. The use of an anthropological perspective in this intervention provides a means of responding to the highly quantified -- and static -- approaches that have traditionally been used in behavioral interventions for autism.

4.5: Ethnography

> "Ethnography is practice and process and product. Game and art. The play of the researcher's imagination across the fabric of an observable portion of our world" (274).

One of the most powerful tools that Anthropology as a form of social research offers autism studies is the ethnography. Ethnography is built on first-hand knowledge

that is acquired in an *in situ* or natural environment.(275) Moreover, ethnographic inquiry is inductive, and open to interpretation by avoiding closed sets of categories. Often intensive, it requires a relatively small population sample and yet serves as a very powerful mechanism for interpreting human behavior. Lastly, though quantitative measurement can be incorporated into ethnography, when done so, it is subordinate to larger themes (274).

An ethnographic approach was selected for this research study due to the fact that the population studied was limited in the ability to communicate. Indeed, 40% of *Active Engagement* participants were nonverbal and an additional 20% were minimally verbal.[10] Ethnography is built upon the concept of studying *culture* and the notion of an autistic culture is somewhat problematic. It is noted, however, that one of the canons of anthropology is that wherever humans are gathered socially, culture will emerge (265). That is, culture is the inevitable product of social interaction, a proposition that was demonstrated clearly in *Active Engagement* outcomes (discussed below).

One of the goals of this project was to capture and document the individual stories as well as this cumulative group *ethos*. A qualitative analysis using ethnographic techniques has also been defined as the most effective means of gaining insight into the behavior of individuals with developmental, linguistic, and perceptual limitations (276).

Ethnography is most closed associated with a methodology termed "participant observation", whereby the researcher witnesses and records by becoming a member of the social setting. This type of approach allows the researcher to take advantage of researcher-participant bonds that are built and gives the researcher the ability to move

[10] Minimally verbal indicates the capacity to speak ten words or less.

more freely through the locational setting (277). A study of Puerto Rican girls, for example, used extensive participant observation to assess how migration, acculturation, and family contexts influenced participant food choices. When combined with interviews, participant observation was situated as a powerful tool for contrasting intentions with actions (278).

Moreover, ethnography is also well situated for this project because of late Anthropology has made profound contributions to the understanding of autism (279-281), "a condition at once neurological and social"(282). If there is no culture of autism *per se,* then anthropology has helped establish a better understanding of those with disabilities in general (279, 280), and with autism in particular (281-284) and their place within the larger social context. Ethnographic perspectives of individuals with autism can demonstrate the ways that they create meaning, engage in activities (whether social or solitary), construct their identities, and pursue their futures (283).

The product of *Active Engagement* was a metaphorical tool kit – rather than a curriculum *per se* – that allows the researcher to move forward onto a broader perspective. This collection of materials that define the toolkit is accompanied by a narrative analysis -- the back story – manifested in case studies of how different individuals passed through the experience. From this vantage point it is possible to generate questions for further analysis regarding the implementation of a nutritional intervention based on food preparation for this understudied population.

4.5.1: Ethnographic Methods in Healthcare and Nutrition

Ethnographic methods have found a strong foothold in healthcare as a form of applied research. Works of this type have analyzed antiretroviral therapy (ART) in urban

Tanzania (285), pain management processes in a colorectal unit (286), feeding in the postnatal ward of a maternity unit in the UK (287), the lesbian experience of giving birth (288), occupational therapy in a sensory integration clinic (289), and tuberculosis treatment among Somali patients in the UK (290). Nutritional studies that have utilized ethnography are varied and include an analysis of how people's decisions about physical activity and diet can contribute to a family intervention (291), institutional ethnography (292), analyzing the perspectives and practices of urban health educators' towards school nutrition policies (293), and perceptions of caregivers regarding nutrition for children in a low income setting (294).

Ethnography offers much potential for better understanding health related contexts in that it requires a greater amount of time for immersion and an appreciable understanding of the forces that shape individual behavior. Likewise, the role of the individual in the drama unfolding must be balanced against an understanding of how these players are situated within the larger context, whether it be a hospital, home environment or salad production class. Mattes analysis of AIDS/HIV patients in Tanzania, for example, demonstrated the significant tension between official medical protocols and the resistance of patients to their perceived disempowerment. The "biomedical truth" of treatment was opposed by patients due to issues of gender, economic constraint, commitment to traditional healing practices, and fear of discrimination (285).

Communication takes many forms though it is unlikely that formal analysis techniques (such as discourse analysis, life history research or content analysis) are

appropriate approaches if the goal is to include individuals covering the range of abilities. For the program to be truly inclusive, an ethnography was needed.

4.6: Case Studies, Interviews, Field Notes, Demographic Information

In the process of utilizing qualitative analysis, a number of data collection methods other than ethnography were also utilized. Case studies (295) are an ideal method when how and why questions need to be addressed, when the researcher has little control over behavioral events and when the focus is contemporary rather than historical. That is, case studies were well situated for the exploratory phase of an investigation such as this initial examination of *Active Engagement*. Data collection for the development of a case study can utilize a myriad of information sources including either participant or direct observations, interviews, tests, examinations of records, and written testaments.

The goal of a case study in reference to *Active Engagement* was to elicit a storyline that explains the course of a participant through the class process, noting the techniques, technology and methods from the toolkit that were efficacious (or not) for each narrative and why they worked (or did not work). Then these chronicles analyzed how the process moved forward, was altered and the ways in which an individual had different strategies for progression through the process. The unique experiences of the participants must be studied independently not combined into one singular analysis that neglects the individual immersion and reaction, and the case study genre is one means for achieving this.

Interviews with caregivers were designed to draw out the patterns of food consumption, the history of eating pathologies, and behavior associated with the

individual outside of the context of the class, as well as how the participant adjusted to the experiences of the classroom [See Appendix A for interview template]. Interview questions addressed formal diagnoses, comorbidities, medications that might affect appetite and favorite and least favorite foods. Demographic information was also collected as part of the interview process and included questions related to age, childhood, siblings and family meal patterns.

Though field notes have traditionally been conceived of as "backstage scribbling" (296), a more sophisticated perception has started to emerge that views them as the product of learned skills that must be built and maintained. In sum, through fieldwork, observation and experience are transformed via field notes into "inspectable texts"(296). The transposing of field notes into ethnography relies on good notes – plentiful, meaningful and comprehensible -- and the researcher's determination to follow the notes towards meaning. Researcher experience with the topic also greatly empowers these notes as meaningful behavior and patterns can be more readily discerned (rather than lost in background noise).

The individually defined events within the class, the surrounding relationships and human interaction, and the sociocultural, physical, and cognitive deficits that filtered the experiences can be understood through exchanges with the participants, interviews conducted with caregivers, videotape and photographs, and written field notes of observations. In their totality, these methods allowed the researcher to create "thick description"(277), or the overall context of the research (297) which serves as the backbone of qualitative analysis.

Chapter 5: Approaches and Framework

The application of health behavior change (HBC) theory and models to explain, predict or guide interventions for the autism population have been relatively rare. This is likely due in part to the fact that the relationship between disability and HBC has not been adequately addressed or defined. This is a significant issue given that the personal and environmental factors for those with disabilities of all types are quite different that those proposed by the most common models (298).

Consequently, autism is presently "under theorized" (281) partly because of the tremendous heterogeneity of the condition, but also due to the difficulty in finding a voice for those with autism. Theoretical perspectives of behavior change for the autism population is an important issue, but is beyond the scope of this thesis. Consequently, instead of choosing a particular paradigmatic approach as the focus, the program design for *Active Engagement* emphasized the methodological process of ethnography and participant observation[11] within the boundaries of the conceptual framework.

5.1: The Conceptual Framework: Active Engagement

Modeled after Hodge et al. (299), the conceptual framework for *Active Engagement* offers an integrated approach for the teaching of life skills by incorporating the three basic psychological needs of autonomy, competence, and relatedness, with the researcher adding an additional component deemed applicable to the population being studied (See Figure 5-1). The underlying assumption of this approach is that when these

[11] Because this study focused on a single class, isolated actions within the class, or a single participant (depending on the style of the case study product) it is more technically a microethnography.

basic psychological needs are met, the learning environment can offer the optimum in security, reduce stress and promote success for those with autism. The construct is composed of four distinct "Motivational Climates" that can lead, when promoted, to unique skills and need satisfactions (See Figure 5-1).

***Autonomy*:** is referenced in the program to support the concept of individual routes of progression. Food preparation is not group oriented in *Active Engagement*. Instead, each individual makes their own salad as best they are capable and, ultimately, chooses all of the defining ingredients. That is, the participant comes to "own" their salad. Self-direction is a large component of this domain with no proper order, system, or method by which to make a salad. Each person defines how and in what order to approach the task at hand. Consequently there are many opportunities for decision-making and follow-through.

Young adults with autism, particularly low-functioning individuals, lead highly constrained lives. A learning environment where they are continually allowed to direct via a decision making process is optimal for supporting independence and for engaging their interest. From the moment participants walked into the classroom, until they departed almost an hour later, the opportunities for choice were continuous.

> **Example:** Each participant was given a pictorial list of possible ingredients at the beginning of each class; they were also welcome to approach the set-up table where all of the ingredients were laid out. Through their list or through direct choice, they decided what ingredients were to go into their salad. Along with ingredients, they were free to determine which texture was appropriate for their salad (i.e., shredded, ribboned, chopped, grated, etc.) and in what order they would like to proceed. In the process of choosing their ingredients, they were compiling a personal, unique salad recipe that was very much their own. But they were also free to make alterations, try new and different items, or remove previously chosen ingredients.

***Competence (Self-efficacy)*:** is a reference point for how confident the participants were in the activities of the class. It was not *their* salad if they could not construct it and thus it was important that they had the proper techniques, tools and attitudes to help master the art of cutting, peeling, pouring, etc. Once competence was gained, it was then important to offer sufficient opportunity to externalize this new-found expertise. At this point, participants ceased learning to make salads and began to explore textures, colors and flavor.

> **Example:** Each participant was provided with their own set of tools: adaptive knife, large bowl, cutting mat and pictorial list of available fruits and vegetables (See Figure 7-1). Working with tools requires motor memory and the participants were taught this with verbal direction or hand-over-hand guidance. Simple songs reinforced proper technique and proper motion. With time, each participant developed the skills to be able to construct their salad independently and required very little assistance.

Relatedness: *Active Engagement* was socially conceived and designed for participants to enhance social skills with fellow participants, hence *Relatedness.* Coming together as a group on a weekly basis and participating in the rituals involved created community (in anthropological terms, culture). Of all the deficits of autism, this is perhaps the most striking but, when appropriately structured, also offers one of the most powerful learning tools. Just as there are tools and methods for teaching how to chop, there are methods, activities and processes that helped the students belong and participate in the larger group.

> **Example:** A simple song strengthened the idea of salad sequences: first this, then this, then that. In the process of participating in this activity, the individuals committed to both salad construction and the social cohesiveness of the entire group.

Preference: Because *Preference* plays such a large role in the framework of

consumption in general (and fruit and vegetable consumption in particular) this was incorporated by the researcher as a fourth component. In some ways the most challenging aspect for a group of individuals with notorious food selectivity, preference was also the most rewarding in terms of obtaining feedback. Those with autism may reject foods forcefully, but they will reject – they are not indifferent to the foodstuffs that are placed before them and will find ways to communicate this.

> **Example:** Each week a new ingredient was introduced and offered to each participant. In the process of choosing whether to partake, they committed to the idea of preference and choice.

These four components were separate pieces of the whole. It should be noted that the conceptual framework offered a solid base for teaching those with autism, but it also directly addressed the factors noted in research for enhanced fruit and vegetable for all populations, with particular emphasis on preference. Mastery of any of the four components needs to be viewed as a success in-and-of-itself given the psychosocial, gross and fine motor as well as cognitive barriers of the participants. The challenge, then, was to provide each individual with the tools, techniques and contexts necessary for mastery of the differing components, with the knowledge that diverse tools were necessary given the differential in both disabilities and abilities.

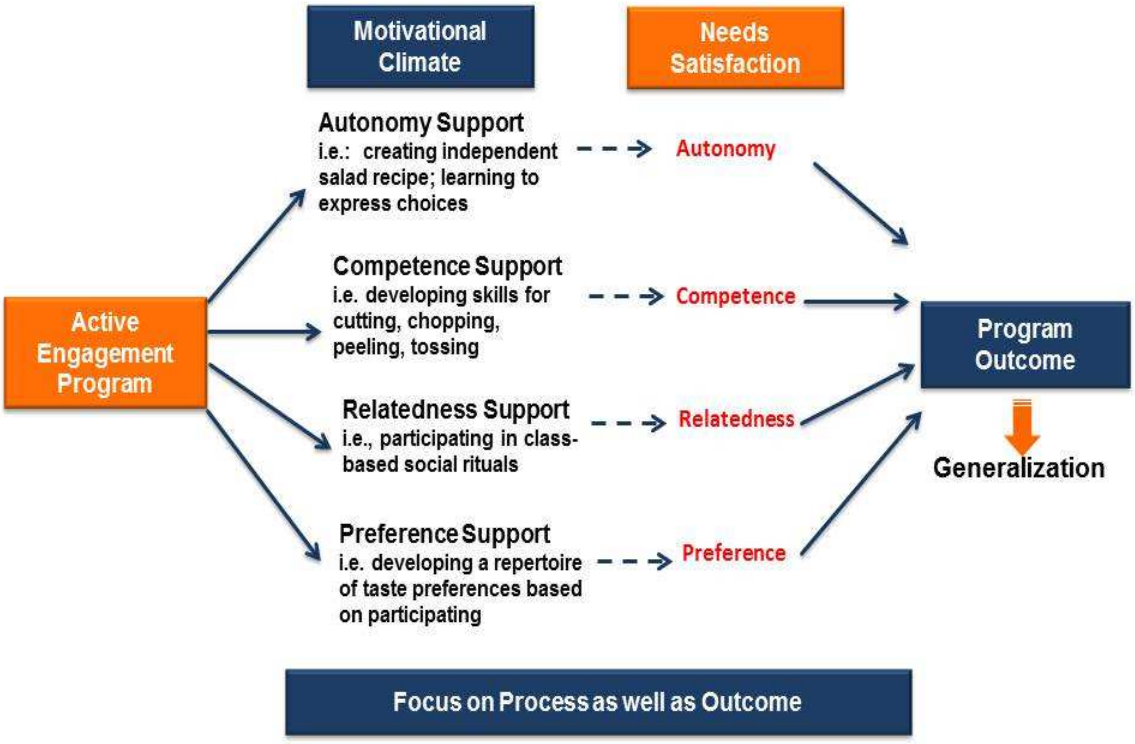


Figure 1. Active Engagement: Conceptual Framework
(Adapted from Hodge et al.: *Developing a Conceptual Framework for Life Skills Interventions*, 2013)

5.2: Intervention Program (Class Process)

A nutritional intervention is typically built on a combination of strategies, used in coordination, that are intended to bring about behavior change (or improve health status) for the group at hand. The program discussed herein incorporated numerous intervention components to create health promotion via an improvement in the nutritional environment (conceived of as "access"). It has been demonstrated elsewhere that change is typically created through three major forces (300): 1) influence over individual's core ideas, beliefs and skills; 2) contributing to the social support; and 3) creating an

environment that supports the change. *Active Engagement* incorporated intervention components that addressed all of these.

These needs were met in varied ways to address individual strengths and weaknesses, hence the reference to the program as a "toolkit" rather than a program manual. Consequently, it is difficult to impossible to describe a singular route by which the course progressed (in other terms, a curriculum). For example, it was anticipated that the *Active Engagement* classes would proceed with an initial focus on autonomy, which held true though individual skill set acquisition was highly variable. In support of autonomy, each student learned to participate as an individual, rather than rely on the assistance of their aide. To assist them in this process, adapted tools were provided and aides were encouraged to disengage; independent action was highly praised. Even so, months after the initiation of classes, some individuals were still experimenting with different adapted materials, struggling with technique, while others had progressed well beyond this to experiment with texture options.

From autonomy, the class generally proceeded into self-efficacy (competence). In this regard, regular weeks of practice greatly assisted their ability to effectively cut, chop, peel and toss. Preference was generally the final component to fall into place as participants developed a personal stake in their salad and it's unique construction. Social relatedness was a progressive condition and was woven throughout the course; participation varied greatly depending on the level of communicative disability.

It is noted here that, though the course had an approximate trajectory, each individual was allowed to pursue their own path. Some individuals came to preference prior to competence or autonomy and the case study methodology utilized allowed for a

detailed explication of these unique paths. Looking at a hypothetical example can help clarify this point. Two participants (Mary A, John S.) entered the program and the following fieldwork observations are noted at baseline:

Key indicators	Mary A.	John S.
Autonomy	Disinterest in choosing ingredients	Disinterest in choosing ingredients, but seems fascinated by color combinations
Self-Efficacy	Relies completely on aide; will not participate in cutting, chopping even when repeatedly prompted and encouraged to do so	Willing to cut and chop, needs lots of assistance from aide due to fine motor delays
Social Relatedness	Does not participate socially or in songs; shows no interest in others in room	Expresses pleasure in the songs, especially when his own name comes up. No interest in others in the class.
Preference	Will eat the salad (prepared by aide) when put before her; second serving as well.	Refused to eat any salad (constructed primarily by self)

At baseline, both individuals have different responses in the realms of autonomy, self-efficacy, social relatedness and preference. Already, Mary A. will partake of the salad, though her aide had indicated she generally ate a highly restricted diet. John S, who is far more willing to participate and somewhat engaged in the activities of the class, is completely unwilling to eat the final product. The class progresses (with systematic and regular data collection) over the course of weeks/months until Mary A. and John S. have new profile data, such as the following:

Key indicators	Mary A.	John S.
Autonomy	Regularly picking own ingredients; willing to try promoted "new" ingredients	Regularly picking own ingredients but highly hesitant with promoted "new" items.
Self-Efficacy	Cuts and chops independently; aide is no longer even sitting next to her	Cuts and chops independently but needs occasional encouragement
Social Relatedness	Participates regularly in the class rituals. Knows the routines well.	Participates regularly in the class rituals. Knows the routines well.
Preference	Eats salad regularly with no prompting. Aides indicate that she has requested salad in contexts outside of the class	Eats salad willingly but only in the class setting

What happens between these two captured moments in time? The journey is individual and different for each participant. Autism as a spectrum is typically conceived as ranging from low to high functioning. What distinguishes individuals in this gamut is not the core deficits but the ability to adapt to the external environment (102). Consequently, each Mary A. and John S. will require unique tools and methodologies to address their unique deficits and it is this individualized approach that distinguish *Active Engagement* as a toolkit rather than curriculum.

Moreover, the *Active Engagement* was conceptualized to work with the entire range of abilities, the only limitation to participation being functional motor skills. Because the program was designed to allow individuals to participate at their own disparate levels of disability, differing styles of learning were incorporated. "Best practices" thus becomes a tool on the individual level rather than the group.

Through the course progression (and the development of the skill sets) the intervention altered the ways in which the participants viewed food generally, and fruits and vegetables in particular. Likewise, the community context created by the program contributed to a social support component. Lastly, the program helped to establish an environment supportive of behavioral change for the participants.

This salad production class was designed to be autonomous, to stand on its' own as a form of *Active Engagement*. It could, however, be easily inserted into a larger cooking curriculum following a logical progression. Table 5-3 outlines the researcher's progressive cooking curriculum. It should be noted that the intervention as implemented was focused on the activities involved in Stage 1. During Stage 1, there is no application of heat, but an emphasis on the primary skills of chopping, cutting, peeling and grating. Because of this, however, the program could involve a larger class and access to fruit and vegetable consumption (via salads) could be introduced directly.

In the basic cooking curriculum designed by the researcher, after introduction to basic cutting methods students typically progress to an emphasis on small appliance cooking involving the production of snacks. Here, popcorn makers, quesadilla machines, toaster ovens, fryers and waffle makers introduce the students to heat application in an environment that simultaneously

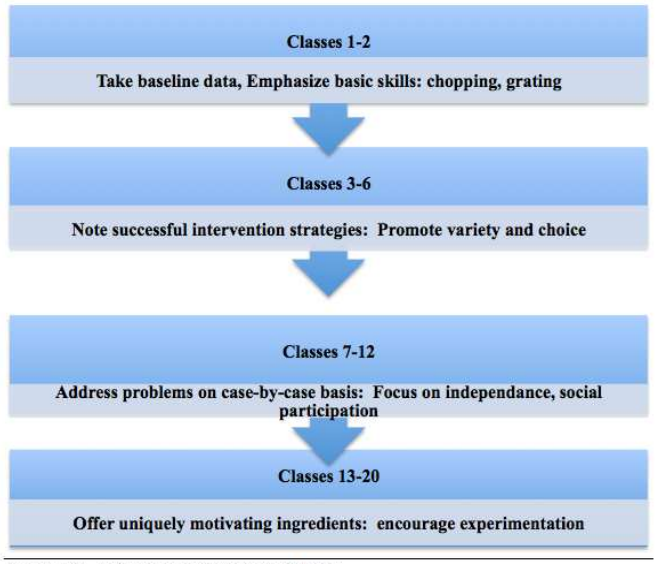


Figure 5.2: Active Engagement Program Flow

emphasizes autonomy and safety. Post mastery at this step, participants are introduced to large appliance cooking and then progress onward to elective options.

Figure 5-2 outlines the projected program flow including step sequences, goals and major approaches for *Active Engagement*.

5.2.1: The Active Engagement toolkit

What resources are required to teach cooking and food preparation skills to special needs students? A wide range of tools, materials, activities, and techniques are required given that the process is so highly individualized for those with autism due to unique sensory deficits, communication disabilities, and learning styles.

> Example: How is an individual with ASD taught to cut or chop vegetables? Table 5-1 offers an explanation of the range of pedagogical options when introducing cutting skills to an individual with ASD. The researcher typically began the course by supplying each participant with an adapted knife. Those individuals who did not adapt well, or reasonably quickly, were moved to another option. Individual with significant deficits in motor planning typically work well with a cutter/popper; this requires only that food be sliced in preparation and then the individual can usually proceed from there to the dicing phase.

Table 5-1: Range of Options for Cutting/Chopping tools

Rip or Tear:
- ✓ If the individual has low muscle tone or difficulty with coordination of right and left hands, it is often best to work without a knife.
- ✓ Lettuce and peppers can be torn or ripped; emphasis can be placed on size of fragments.
- ✓ As the course progresses, this technique can also be used with individuals who have already mastered adapted knives as a useful approach to introduce variety and change into the curriculum.
- ✓ Scissors can also be used on lettuce.

Adapted Knife with Stabilizer:
- ✓ Individuals who struggle with right/left hand coordination but have reasonable grip strength, might do well with an adaptive knife.
- ✓ A fork is used to stabilize the object being cut while the knife cuts through the material.

Adapted Knife with Proprioceptive Input:
- ✓ Individuals who have adequate right/left hand coordination but have issues with grip strength are well suited to use the adapted knife along with proprioceptive input.
- ✓ This can come in the form of mild pressure on the cutting hand or can involve the use of wrist weights.

Adapted Knife:
- ✓ Using the adapted knife on its own works well for the majority of individuals.
- ✓ This works well to teach how to position vegetables without "cutting" fingers.
- ✓ It is also excellent for teaching the back/forth motion needed as the serrated edge of these plastic knives are not particularly efficient with only a downward motion.
- ✓ The ergonomic handle is designed to be held by children ages 4 years and up and conformed to the safety requirements of Toy Safety Standard ASTM F963 for minimal risk.
- ✓ Despite the fact that they are regulated as toys, such knives are utilizable as functional tools in a kitchen setting.

Roller Knife:
- ✓ This tool allows for continuous cutting and works well with lettuce, peppers, and celery.
- ✓ Though the motion is easy to learn, the positioning hand is vulnerable to the blade.

Food Cutter and Popper:
- ✓ This popper chops into small even pieces and pushes the uniform pieces through a sieve.
- ✓ This tool requires little fine motor control but does need physical strength.
- ✓ Not particularly useful for chunky vegetables.

Cutting Knife with Cut-Resistant Glove:
- ✓ Individuals who have mastered the adapted knife can proceed to cutlery; it is wise to use a safety glove with wire mesh to ensure that the transition is a safe one.
- ✓ The glove protects the stabilizing hand only and safety remains a priority for other components.

Independent Knife Use:
- ✓ It is often best to begin with dull knives, or knives without blades (butter knives) before transitioning to authentic cutlery.

Table 5.2: Active Engagement – Goals and Major Activities

Construct	Goal	Approaches	Step sequence
Autonomy	Strengthen self-direction, decision making, motor memory Support individual routes of progression Focus on verbal direction or hand-over-hand guidance	Each participant is given a pictorial list of possible ingredients Check those items that they would like in their salad for the next week Compile a personal, unique salad recipe that is very much their own	Step 1 (initial focus)
Self-efficacy (Competence)	Learn what a salad is Mastery of preparation techniques to the best of their ability: cutting, chopping, peeling, grating	Sequencing of salad production Simple songs reinforce proper technique Tool modifications for those who struggle Internalize the procedures through practice; externalize learned skills through independent production	Step 2
	Focus on sensory development (textures, colors, flavors)	Externalization of skill creates new interest in differing vegetables. Hands on manipulation of many differing vegetables promotes understanding difference in texture and color	Step 2-2
Social-relatedness	Create a class-based community Create a sense of social belonging in a population with marked social deficits	Songs specific to the group create social cohesiveness Class rituals are shared by the participants and externalized in behavior	Step 3
Preference	Establish fruit and vegetable consumption as a preference in a population marked by food selectivity	Continual emphasis on taste rather than nutrition Graphing to encourage tasting of new ingredients Define preference as uniquely individual, rather than communal With time, participants develop curiosity about new ingredients, rather than suspicion	Step 4

Table 5.3: Salad Class as Part of a Larger Cooking Curriculum

Stage 1: **Learning to Chop, Cut, Peel, Grate**	Salad Production Class: Individuals are brought together in a social setting and taught the skills necessary to make individualized salads. Emphasis on technique (chopping, grating, shredding, etc.), color, texture, and overall participant independence.
Stage 2: **Introduction to Small Appliance Cooking -- Simple Recipes/Snacks**	Simple Recipe/Snack Class: Individuals are introduced to small appliance cooking in cooperative dyads or triads. Low tech, low risk appliances are utilized including toaster, microwave, quesadilla maker, waffle iron, blender, electric griddle, hot pot, ice cream machine, toaster oven, etc. Emphasis on safety, choice, and participant independence.
Stage 3: **Introduction to Large Appliance Cooking**	Meal Production: Individuals in cooperative small groups plan and prepare their own meals using stovetop and oven. Emphasis on kitchen safety, meal planning and participant independence.
Stage 4: Introduction to Elective Cooking	Individuals elect courses that match their interests. Some possible course ideas include: - Introduction to baking - Exploring Ethnic Cuisine - Preparing Family Meals - Bread Making Emphasis on kitchen safety, participant choice and independence.
Stage 5: Generalization	Skills acquired in the course are brought into the home/residential environment. Through communication with caregivers, the participant attempts to utilize acquired skills in the home kitchen. Emphasis on re-enforcement of lessons

5.3: Intervention duration

Active Engagement duration was formally prescribed at 25 weeks. Though the *Active Engagement* classes have continued to take place at CSS, data collection has now ceased. It is believed that in the six-month progression of the class, data saturation was reached. In

qualitative studies this is believed to occur when the researcher is no longer observing new behavior in response to an intervention.

5.4: Future Applicability of Program

The conceptual framework discussed above provided the structure of the program, not the contents. The intent of such is that the program could be implemented in a different context, in support of a specific nutritional goal other than salad production. In the research discuss herein the conceptual framework was utilized so as to enhance access to fruit and vegetable consumption and introduce introductory cooking skills, but other objectives can be accommodated by the conceptual framework.

> **Example:** CSS supports a breakfast program whereby aides set out food in the kitchen for a group of approximately 8 individuals with autism/ID. Typically, breakfast consists of juice, apple slices and crackers or pastry. Incorporating the conceptual framework into this context could contribute greatly to the nutritional intake of all involved in the following ways:
>
> Autonomy: Individuals would be required to prepare their own breakfast to the extent of their capabilities. Choice would be fundamental: for example, choice among English muffins, whole grain bread or bagels. Or, between yogurt/fruit or oatmeal.
> Self-efficacy: The individuals would be taught to utilize low-risk utensils to prepare the food items. For example, participants could choose to make toast, spread jams or cream cheese on their bread or slice fresh fruits.
> Preference: Just as in the salad making class, in the process of preparing their own meals, preferences would be enhanced along with diet variety.
> Social relatedness: Through participation in the rituals of this group, they develop a sense of their own place in the social setting of the breakfast program.

Consequently, the conceptual framework provides an appropriate model for a variety of differing contexts and nutritional goals for this population. The basic program

and the underlying mechanisms behind it (autonomy, self-efficacy, social-relatedness and preference) are easily transferrable beyond the original context.

5.5: Expanding the Active Engagement Program

There are several ways that *Active Engagement* could be expanded at CSS beyond the initial research described here. Adaptations could include:

a. Having participants graduate to the higher skill level

If the salad production course were subsumed into a larger curriculum, (see Table 5-3) *Active Engagement* could become the basis for a comprehensive life skills approach to cooking. Under this plan, individuals who had mastered the basic skill sets involved with chopping, cutting, and peeling could move on to another socially-based course where additional skill sets could be introduced. The topics that can be incorporated into such an approach are diverse and include:

i. Cooking methods: learning how to safely utilize oven, stovetop and various small appliances.

ii. Menu planning: learning how to browse electronic and print media for appealing recipes

iii. Shopping: learning how to order appropriate materials for specific recipes

iv. Serving: learning how to prepare and present meals

v. Cultural: learning the cultural practices related to meal creation and presentation

b. Generalization of the skills learned in salad class

In this adaptation, having mastered the class the individual would be given the necessary support to prepare a salad outside of the classroom context. This could include:

i. Working with parents/caregiver or residential aides to transfer the tools and materials into the home environment; providing the necessary physical and social support to create a salad;

ii. Creating a communication network that allows parents/caregivers and residential aides access to web-based resources that will assist them including:

a. Video modeling of techniques

b. Video of the individual making their salad in class

c. Sample "My Salad Recipe" recipe sheets and access to adaptive technology

c. Creation of a CSS program based on the idea of a weekly community salad bar

In this scenario, the individual – having developed the ability and preference for an individualized salad – would be allowed to transfer acquired skills into a different environment. A community organized salad bar would allow the *Active Engagement* components of preference, self-autonomy, self-efficacy and social-relatedness to be *writ large*.

All of the options are highly viable, given the tremendous support that *Active Engagement* enjoys at CSS. It remains to be seen how the course will evolve, though for the present there is no plan to discontinue the two classes.

Chapter 6: Data Analysis

6.1: Qualitative Analysis and Autism

Qualitative research and analysis can be described in many ways (interpretive, naturalistic, emergent, exploratory, inductive) but it is especially pivotal in hypothesis generation (rather than hypothesis testing): "Assessment 'emerges' from data, rather than being determined ahead of time and the aim is to develop an in-depth understanding of particular cases or circumstances"(297). As such, it plays a particularly powerful role when attempting to explore new areas of research. While biomedical and positivist studies of autism typically focus on quantitative approaches, the qualitative dimension provides a powerful tool for amplifying rich meanings and lived experience for this very heterogeneous population.

Qualitative analysis is built upon the premise of incorporating participant perspective, which implies a level of communication that is not always applicable for those with autism:

> To have a perspective, one needs *language* [emphasis in original]. To have a perspective means to formulate an individual vision, opinion or narrative about the world that represents your experiences. Consequently, if you cannot speak or fill out questionnaires, you cannot produce a perspective (301).

Often individuals with autism may be physically capable of actual speech but lack the cognitive ability to provide verbal answers that are meaningful in the context of research. Though there has been extensive qualitative focus on the ways in which parents and health care providers experience autism (14, 284, 302-313), there has been much less research directly addressing (or rather incorporating) those who are autistic. Research that includes the autistic voice – the "privileging of informant voices" – does exist (279,

289, 314-320) but typically focuses on high functioning individuals or those with Asperger's Syndrome. Qualitative analysis was utilized specifically for this study so as to involve that part of the spectrum that often is ignored in research and interventions.

Using an ethnographic approach and a case study methodology allowed the researcher to move beyond this challenge by viewing behavior as a response in and of itself. That is, each individual *expressed* as a result of interactions with others and a material world. This is especially true in the realm of food consumption, where preference is not difficult to discern. In the act of eating, any individual will "enact certain appreciations" (301) and in a population with notorious eating patterns, the act of eating is – in an of itself – a powerful form of communication.

Participant observation as a methodology allows the researcher to join the participants at the table, to observe and – when patterns begin to emerge – to define in meaningful ways. Experience and a foundation in the background literature then serve as a means for the participant observer to transform these unstructured observations into patterns of meaning.

6.2: Data Analysis Strategies

> "Whatever the content, stories demand the consequential linking of events or ideas. Narrative shaping entails imposing a meaningful pattern on what would otherwise be random and disconnected"(321).

Interpretation proceeds for the researcher through raw data analysis. Traditionally this has come to imply either the stories of participants captured by a researcher, or derived accounts built on observations by the researcher (i.e., fieldwork) (322). Typically these observations – collected as field notes – are brought together to form a plot line

built upon a temporal dimension (even if only sequential) to create an *ethnography*. When this narration captures the unique experience of a participant in the program, it can also be understood in the health sciences as a *case study*.

Following Yin, (295) it is important to note that the analysis of case study data is not a science and each practitioner has their own means of approaching the data. The goal is to find the patterns inherent in the material collected and this can be achieved in numerous ways, depending on the type of data and how the researcher is most comfortable proceeding. Yin divides analytic strategies into four general categories: utilizing a theoretical perspective, playing with data to arrive at a theoretical perspective, using descriptive categories by which to organize the material, and contrasting with rival or differing explanations of the data.

For the case study that analyzed the events surrounding Paul's accident (Chapter 8) analysis was undertaken by "playing" with observational notes as well as the information that emerged from an extended interview with Paul's father. Using a temporal dimension to compare Paul's behavior before and after the accident, allowed a story to emerge that made sense of the events given the researcher's appreciation for newly emerging research. An alternate explanation was proposed for this data, but the researcher found this substitute interpretation to be less satisfying given the increasing understanding of the pain response in autism.

In Chapter 9, the researcher applied a different analytic strategy for her examination of parental interviews. Here, descriptive categories provided a framework to help filter and make sense of the immense amount of data that emerged from the structured discussions.

Though Chapter 8 and 9 provide very different ways of working with and analyzing the data collected, both approaches to case study still found a way to provide insight into a population that typically cannot speak for itself. After all, one of the researcher's goal in utilizing qualitative analysis was to allow those with communication disorders, such as autism, to have a voice to define their experience:

> "... too frequently, the difficulties in interviewing those who are less articulate are viewed in the context of their deficits, not in that of the limitations of the method being used. Therefore, the way forward should focus not on further legitimizing the exclusion of individuals with expressive language deficits from qualitative interview research but in finding effective means to overcome the challenges posed by their inclusion" (323).

It is the researcher's belief that these types of challenges have been addressed herein and that those without ability to verbalize were adequately incorporated (given a voice) in *Active Engagement* conclusions.

6.3: Data Organization

Field notes were transcribed as soon as possible after the class and video and photos were cataloged immediately. Interviews were taken long hand and collected. These forms were transcribed into a Word document only when all 13 interviews had been completed so as to allow for the maximum comparative power. Interview forms, transcribed notes, collected demographics, videos and photos were kept within a locked cabinet at all times except when they were being utilized, edited or analyzed. All data collection and storage methods were submitted to and sanctioned by the Institutional Review Board at the University of Maryland – College Park.

6.4: Reflexivity, Bias Control and Validity

Always and everywhere, the qualitative researcher needs to bracket their experience. That is, it is vital for the investigator to actively analyze the preconceptions and biases that may affect how data is collected, analyzed or interpreted. This concept, better understood as reflexivity (265), is said to situate the researcher within the project (277) and is especially important in a qualitative endeavor where the researcher is the primary instrument of exploration: "A credible, authoritative, authentic, and trustworthy voice engages the reader through rich description, thoughtful sequencing, appropriate use of quotes, and contextual clarity so that the reader joins the inquirer in the search for meaning" (265). The researcher's position in the research should never distract from, or call in doubt, the conclusions of the study.

There is no single approach to the issue of quality and validity in qualitative studies (277) and some practitioners (324) even argue that validity in qualitative research should be rejected in favor of the researcher simply being systematic and organized. It should also be noted that in heath care contexts the terms "trustworthiness" and "authenticity" are often used in lieu of validity and reliability.

This research study relied heavily on data triangulation, or obtaining information from a multiplicity of sources in numerous ways, for support of outcome validity. Here, resources included not only the unstructured observations of fieldwork (field notes), but also the structured interviews with parents, as well as photos and video, and the background knowledge (both practical and literature based) gained from the researcher's experience with this population. Triangulation is believed to contribute greatly to

research trustworthiness and provide additional support for research reliability and validity.

The topics of methodology and data analysis will be revisited in greater detail in the individual chapters addressing *Active Engagement* outcomes (Chapters 7, 8, and 9).

Chapter 7: The Overall Trajectory of *Active Engagement*

7.1: Implementing Active Engagement: An Ethnography of the Course Progression

As described in Chapter 5, finding a voice for those with autism requires moving beyond a particular paradigmatic approach, though anthropology has made profound contributions of late to our understanding of this condition (279-281). Ethnographic perspectives of individuals with autism can demonstrate the ways that they create meaning, engage in activities (whether social or solitary), construct their identities, and pursue their futures (283). *Active Engagement* offered a unique opportunity for individuals with autism to develop cooking skills in an environment that encouraged their independence, built their confidence and created a group identify for them to participate in. This ethnography is designed to demonstrate these processes.

Here emphasis is placed upon a methodological perspective, in this case ethnography and participant observation, rather than a theoretical perspective of how health behaviors are changed. As a nutritional intervention, *Active Engagement* is designed to work with both the strengths and deficits of young adults with autism. Consequently, this ethnography incorporates procedural reasoning to address the functional goals of the course progression as well as narrative reasoning to address the individual responses noted among the participants. In some ways this is a classic etic and emic distinction: a careful attempt to include the events and activities that were important to the ethnographer as well as those that were meaningful for the students.

Though ethnography is relatively new in autism studies, it is an ideal means for working within a heterogeneous population given that it simultaneously serves as a methodology as well as an interpretive mechanism of human behavior. Moreover,

Anthropology offers a number of unique perspectives for both collection and analysis of data, particularly in reference to autism (283). Anthropology has long specialized in heterogeneity ("otherness"), with emphasis on intersubjectivity[12] and a focus on the senses, all common subjects of interest for investigating those on the spectrum. Anthropology, moreover, is inherently reflexive and natural in context.

Most importantly, an ethnographic approach was selected for this study of young adults with autism learning to cook because significant communication deficits were noted among the participants; 40% were nonverbal and an additional 20% were minimally verbal. The traditional methods of data collection such as interviews, dietary recalls, pre and post-tests of ability were neither practical nor even possible. Ethnography is built upon the concept of studying *culture* and the thick description in this account will make clear that a social ethos did emerge during the course progression, despite the social deficits that are diagnostic criteria of autism (265).

Though the conceptual framework for this program was constructed so as to be applicable to almost any social group, specialized tools and techniques were collected, tested and applied for this particular at-risk population. In so doing, the goal was to help participants in the development of self-autonomy, self-efficacy, social relatedness, and preference. It was hypothesized that advancement of these factors, combined with access, would contribute significantly to building increased dietary variety and to enhancement of preference for fruits and vegetables.

The objective of this ethnography is to provide an overall view of the course trajectory, to capture the transformational processes, and to offer insight into the wide

[12] Intersubjectivity addresses the relations between people.

range of responses and behaviors noted by the researcher over the 25-week course progression. As such, it is a starting point for further analysis and course development, rather than a final consideration.

7.2: Participant Observation

Ethnography is a product, in that it is constituted as an end result (i.e., this chapter). But it is also a process in that it is a method of inquiry utilized to study human behavior. Data collection in ethnography can be done through various means, but the primary source of information for this analysis was field notes collected via participant observation carried out by the researcher.

Participant observation can be defined as a data collection method in which the researcher joins in the very activities being studied. It is widely understood that the process itself is highly individualistic and heavily influenced by the specific context of the fieldwork. For example, female researchers studying male phenomenon are limited in how completely they can immerse themselves given gender constraints.

Participant observation can be found to be a continuum ranging from complete observation to total participation (325) with many notable and influential scholars covering the ground between these two extremes. It is generally accepted that there is no formula for the exact balance but, instead, the positioning of the researcher in the process is an indicator of the their analytical position.

In the *Active Engagement* classroom, the researcher was highly engaged, continually interacting, and rarely had an opportunity to take the passive role of observer. She was both researcher and instructor and was responsible for noting behavior but also

had to ensure at all times that the class was running smoothly. Consequently, in this accounting the researcher skewed heavily towards an activist role, due in part to both experience and personality. The researcher had significant skill interacting with this population, and was comfortable doing so. She also presented with a high affect to her class participants, a style that often works well for those with communicative and social deficits. It should be noted, however, that other approaches (less involved) can also be highly effective. Indeed, it can be hypothesized that had the researcher been less interested in effecting behavior change, new independent-oriented behaviors might have emerged in-and-of-themselves and a less activist researcher stance might have even been beneficial.

Skill sets involved in participant observation are numerous and include interviewing (informal and structured), recording of notes, attention to detail, active listening, ability to 'read' the room, and the development of attention span. But two that are of particular importance are the development of memory and patience, highly useful but somewhat abstract in terms of actual skill acquisition. Memory involves the ability to observe an event, interaction, or even absence of behavior, internalize both the event and it's meaning, and then externalize at the point when note taking becomes possible. This skill does emerge and mature over time and is one of the reasons that lengthy fieldwork opportunities are often so productive. Patience as a skill involves the development of an ability to let events happen naturally, rather than continually trying to serve as a catalyst.

While these various aspects of participant observation create a powerful data collection technique, the limits of this type of methodology must be noted. After all, physics has long understood that in the process of observing a phenomenon, the

phenomenon itself is altered, as is the observer. This phenomenon requires acknowledgement and reinforces the importance of researcher reflexivity, or a conscious understanding of where the investigator is positioned in the study.

7.3: Methodology

Active Engagement was an introductory cooking class teaching basic skills (chopping, cutting, grating, shredding, etc.) to young adults with autism and other developmental disabilities. The focus of the class was on producing individualized salads given a wide array of ingredients (primarily vegetables, but also fruit, and energy dense toppings). All aspects of the course were designed, organized and maintained by the researcher.

Active Engagement was held for 25 consecutive weeks with two separate and non-overlapping sessions on Thursdays and Fridays at 11:00 am in the CSS kitchen; the only disruption to the schedule was on holidays such as the Fourth of July. Supplies were purchased by the researcher for both classes on Thursday mornings at a local grocery store (See Figure 7-3 for visual of purchased vegetables). The researcher was responsible for cleaning all of the various ingredients as required and for set-up of all of the various toppings, dressings and other ingredients.

Attendance was relatively stable across the course progression, though individuals occasionally exited the program for vocational or educational opportunities that arose. Nine individuals were enrolled in each one-hour class, though typically at least one participant was missing from any given class, usually for health or scheduling reasons.

On a few occasions during the summer vacation period, attendance was particularly light with less than half of the expected participants in attendance.

Through involvement in these weekly classes, and through observation of individual practice and behavior, the researcher was able to weave together a narrative of the course progression. Over the course of 25 weeks, observations were collected during each class. Note taking addressed each participant, recording novel behavior as well as patterns – both the unusual and the ordinary. Activities and occasions were also the subjects of information gathering. Some notes taken by the researcher were extensive and covered in great depth the details of an event or encounter in the *Active Engagement* classroom. Other notes addressed mundane events that simply demonstrated generalized behavior patterns, or the ways that individuals created their own patterns of participation. The overall goal of note taking was to create the "thick description" that ethnography relies on to paint a sociocultural picture.

Collected field notes were typed up at the end of each class into a spreadsheet and were reviewed regularly for idiosyncrasies or patterns of note. Pictures and video were also collected and studied as part of this same process. Storage and maintenance of these various data sources were submitted to and sanctioned by the Institutional Review Board at the University of Maryland – College Park.

7.4: Methods of Analysis

Ethnography is a form of data collection but the details are typically left to the practitioner as to how to interpret and explain behavior. Most researchers attempt to move beyond a simple cause and effect relationship, often by drawing on theoretical

perspectives that typically will frame the phenomena under investigation. But, as previously discussed in Chapter 5, in the context of *Active Engagement* there is no underlying theoretical perspective or paradigm to serve as an interpretive filter. Instead, the interpretive focus relies on the procedural issues of data saturation, reflexivity and applicability.

Data saturation occurs when the researcher is simply not longer observing new behaviors. This is somewhat unlikely in a heterogeneous population such as autism where the range of behaviors demonstrate is tremendous. Instead of a lack of demonstration of new behaviors, the researcher identified saturation as the point in which new behaviors emerged less frequently in the classroom.

Reflexivity references how the researcher's prior assumptions and experience shaped the program outcomes and research expectations. Here, the researcher readily acknowledges that, despite her extensive experience working within this population, she was still left unprepared for the powerful social forces exhibited in the *Active Engagement* classroom. The fact that she was able to acknowledge this phenomenon is evidence of an ability to look beyond the expected and to see more than what is expected. Reflexivity also moves beyond this idea to acknowledge that all the behaviors in the classroom need to be observed, including that of the researcher. This can be posed more explicitly to ask not *if* the researcher is biased, but question *how* the researcher is biased (325).

Lastly, applicability references what in quantitative studies (297) is typically deemed generalizability or external validity. The issue of applicability for *Active Engagement* in other contexts within CSS was discussed in Chapter 5 but it should also

be noted that the program is designed specifically for young adults with autism and would be appropriate in any context where this population is situated. Thus, applicability of the program is believed to be demonstrated for this population.

While these varying components of qualitative analysis contribute to the final account, it should be noted that the actual techniques of analysis in ethnography are mutable:

> In ethnography the analysis of data is not a distinct stage of the research. In many ways, it begins in the pre-fieldwork phase, in the formulation and clarification of research problems, and continues through to the process of writing reports, articles, and books. Formally, it starts to take shape in analytic notes and memoranda; informally, it is embodied in the ethnographer's ideas and hunches. And in these ways, to one degree or another, the analysis of data feeds into research deign and data collection (274).

Notes were reviewed in a continual process that raised questions, caused previous conceptions to be discarded, and required the development of new approaches and techniques to address problems that arose. The researcher's analytic process was iterative and heavily reliant on the conceptual framework (see Chapter 5) for guidance. Much of the data collected was unstructured, here intended to imply that the collected information was not previously constituted to be applicable to any previously defined analytic categories (274). The focus of study alternated between raw data and emerging themes that helped to create a version of events that made sense, both to casual readers as well as experienced practitioners in both autism and nutrition research.

One of the limitations of this ethnography is the researcher had two dual (and sometimes opposing) responsibilities: interacting/intervening in an attempt to alter behavior, and simply observing to see how participants would respond independently.

The researcher took an activist role in the *Active Engagement* classroom, but there were times when these dual responsibilities clashed.

What follows is a summation of class progression that attempts to draw on the many observations taken over the course development, and from multiple frames of analysis, to describe the activities that comprise *Active Engagement.* In its' totality it is argued that the ethnography captures the reality of the classroom and accurately describes the phenomena being studied (275).

7.5: Class Procedures

All *Active Engagement* participants were accompanied to the kitchen classroom by their personal aide. This aide was responsible for their client's behavior, class attendance, and implementation of a behavioral plan, if warranted. It was the aides' responsibility to coordinate with the instructor as to schedules, missed classes and adjustments that needed to be made for their client. The aide was also required to remove a client if behavior or safety became an issue though this was only a significant problem on a handful of occasions. When classes became especially chaotic, aides typically helped distribute ingredients and worked to resolve issues that arose. If all was quiet in the kitchen classroom, many aides would proceed to construct their own salad, working side-by-side with their client.

A typical *Active Engagement* class would begin with participants entering the kitchen classroom at varying times over a fifteen-minute window. Class progression was non-synchronous and thus could accommodate diverse schedules. One young woman,

Lindsay[13], often arrived very late to the class due to regular delays in her daily program. Consequently, Lindsay would often be just starting her salad construction as other participants were consuming their final product. Though the class accommodated her late arrival, Lindsay did miss out on some of the social components of the class.

On average, participants could complete all of the class objectives (including set up, construction, consumption and cleanup) in approximately 45 minutes though one individual (Ajay) could be done in 30 and another (Johannes) would require well over an hour. Thus, an observer walking into the middle of an *Active Engagement* classroom would note individuals in varying states of salad production, rather than a class progressing at the same rate of production.

A routine was developed for each individual relatively quickly in the progression of *Active Engagement* that set the framework for all subsequent classes. Because it was knowable and predictable, it allowed individuals with autism to learn the procedures and adapt to the class rhythms. That is, participants knew their role, how to proceed, and what to anticipate – all highly desirable for individuals with autism who thrive on routine.

7.6: Participant's Role

At the beginning and end of the *Active Engagement* sessions, the participants were responsible for set-up and breakdown of their workstation. Tasks involved included the following:

Hand washing: After first entering the kitchen classroom, students would begin the class process with the ritual of washing their hands at the sink. This procedure was

[13] All names used are pseudonyms.

overseen by the participant's aide using highly personalized procedures and, often, hand-over-hand guidance. There has been limited research on comprehensive approaches for teaching hand hygiene to the disabled, despite the fact that those with special needs require more assistance and detailed instructions for routine care. Moreover, hand washing is one of the most important methods available to reduce or prevent the transmission of pathogens in both public health and cooking contexts. As *Active Engagement* continues to develop, one of the program goals is to introduce a hand-washing component to the class curriculum that will address many of the motor deficits experienced by this population.

On occasions where the salad was to be distributed to others or for special salad assemblies, the participants would wear loose fitting plastic disposable gloves that are easy to pull on and off and which are designed for food preparation purposes. These gloves were not used, however, for the standard class sessions as they made holding and stabilizing the salad ingredients more difficult, and easily interfered with prevailing sensory abnormalities.

Seating: Upon completion of hand washing, participants would find a place to sit in the kitchen area. There was no seating chart, and individuals were seated according to routine and preference around a large table with seats around the perimeter. Aides were careful to ensure that individuals with challenging behaviors were appropriately seated and that participants who might clash were kept apart. A small table was also set off from the center of the room for those individuals who struggled when there was too much sensory input and needed to work separately. Most participants preferred to work at the main table.

Set-Up: After the participants had found their place at the main table, it was time to set up their workstation. Over the 25-week course progression, participants demonstrated a wide range of behaviors in the development of this skill set. Moreover, independence in set-up was heavily influenced by the aide's willingness to push their client. Some aides demanded increased self-sufficiency routinely by refusing to help their clients with this basic task. Other aides jumped in too quickly to provide assistance, as it was the easiest way to prevent client frustration from developing. In general, however, all aides stepped back from being overzealous when their clients were doing the actual cutting and chopping, so a high level of independence was achieved in terms of the development of preparation skills.

While some individuals were capable, but dependent on prompts to acquire set-up materials, others could find their way to collect all the needed materials on their own. Several individuals could start the process of set-up, but easily became distracted and had to continually be redirected back to the task at hand. One possible suggestion for future development of *Active Engagement* is to offer a picture version of the workstation (Figure 7-1), perhaps in a placemat type of format, so as to assist with enhanced independence of setup.

Ready to start: Once the set-up of the workstation was complete, the participant had to determine how they would like to begin the salad construction process. Whether verbally or through use of the ingredient inventory (i.e. pointing to a chosen item), individuals would indicate a starting point and the salad construction process would commence. On quiet days, certain individuals were allowed to pick out their own vegetables directly at the counter, but in a typical class the room was highly congested

and participants were encouraged to remain in their seats and have the chosen items brought to them.

It should be noted that during the early classes, the participants demonstrated high levels of anxiety, which is typical given that the class rituals and process were unknown, an therefore unpredictable. As the class evolved and began to follow an expected path, anxiety (as demonstrated in outbursts, echolalia, or hand-flapping) declined. Indeed, as class progressed the class rituals could be used as a tool to redirect challenging behaviors.

Closing: At the completion of the class, participants were responsible for cleaning their station, placing their equipment in the sink and returning any unused materials. Many participants (i.e., Ajay, Yvonne, Johannes) would eat their entire salads; others had remainders that were typically offered to those individuals arriving in the kitchen for the lunch hour. In general, waste was low and any leftover vegetables were given to the CSS chef for use in other kitchen programs.

7.7: Instructor's Role

The role of the instructor was varied, with numerous responsibilities to maintain the class and set the tone. These responsibilities included:

Creating a work station for students: The *Active Engagement* workstation (Figure 7-1) was composed of the following materials: 1) bowl; 2) cutting mat; 3) adapted knife, peeler, and spoon; and 4) an ingredient list. A grater was typically made available as well. It was the responsibility of the instructor to ensure that there were sufficient supplies of these tools and that all were in clean and in good working order. It was the responsibility of the participant to set up the actual workstation.

The *Active Engagement* workstation was intended as a place to construct a salad but it was also meant to serve as a discrete classroom, given that sensory abnormalities preclude any form of teaching with techniques related to joint attention. Instead, all of the learning in the *Active Engagement* classroom is intended to occur directly in front of the participant: through experimentation, through social observation of peers, or through direct modeling from the researcher. In this way, learning was hands-on with plenty of opportunity for exploration, but also supportive of class ritual and habit.

Figure 7-1: *Active Engagement* Work Station

Using ingredient list to promote independence and to indicate preference: To assist in encouraging as much independence as possible, an ingredient list (Figure 3-1) was developed to provide a visual reminder of what was available for the participants to utilize in the construction of their salads. For the first few sessions, the instructor asked the participants to peruse the list at the end of the session and choose what they would like for the next class. The premise of this activity was that participants would be "ordering" what they would like to have available for the coming week, and thus indicating preference. This activity required participants to utilize planning skills and also gave them an opportunity to build a recipe, make decisions, and help shape the future direction of the class.

Using the ingredient list in this way was also a useful tool for encouraging participants to make changes from their typical patterns. For example, Samar, a young women with excellent verbal skills, had been enjoying ranch dressing for six consecutive classes. She used the occasion of filling out her ingredient list for the next week as an opportunity to pick -- and announce dramatically to the class -- a different choice of salad dressing for the coming week.

On another occasion Stacey, a young women with diverse developmental disabilities, handed back her ingredient list with very careful choices noted; it was clear that she had taken the effort to thoughtfully completed the sheet and had not rushed through the task. The researcher, surprised, questioned her because peppers had not been chosen and on several occasions the researcher had praised Stacey for the skill she had exhibited in preparing her peppers. Stacy, quietly shaking her head, said "No, I don't like peppers." Stacey had included peppers in her salad every week up to that point only because they were put in front of her by her aide. Given the explicit opportunity to choose, however, Stacey had rejected the peppers. Not all participants were so acquiescent, but from that point onward an unofficial rule was established such that ingredients were never simply placed in front of a participant. Instead, they had to be specifically requested or chosen in some direct communicative manner.

For some individuals the use of an ingredient list was a powerful means of indicating preference, a form of self-autonomy, but for others it was confusing and resulted in the checking of every box on the list or just one box to indicate their favorite item. For example, Rick routinely checked the box for cheese each week and nothing else – a profound referendum on his favorite ingredient.

Using the list consistently as an ordering form also could be a negative in that it gave participants an opportunity to manifest behavior rigidity through choosing the same ingredients repeatedly. Likewise, the end of class (when the "ordering" for the next class was done) was chaotic and, due to this, participants may have rushed through the process in their haste to move on with their schedules.

Because of these various factors, after several months the instructor ceased to use the food inventory as an ordering mechanism and, instead, incorporated the list into the workstation as a regular aid for salad construction. This was particularly important for those individuals who were nonverbal as it gave them a means to express themselves in the realm of preference by supplying a means of augmentative communication. Thus, Ajay, for example, could point to a tomato on his inventory list to indicate what he would like, though he was incapable of verbally expressing this request.

Over time the ingredient list changed greatly reflecting group and individual preferences as well as seasonal options. A variety of energy dense items were added including avocados, hard-boiled eggs, chicken breast, won ton strips and a variety of new salad dressings. Inclusion or exclusion of these items reflected variations in popularity as typically such items waxed and waned in preference over time. What was accepted early in the class progression (i.e., three bean salad) might fall from favor after several weeks as participants grew weary of it or new ingredients eclipsed it.

Vegetable choices on the ingredient list were fairly constant though mushrooms, shredded cabbage and broccoli slaw were later additions. Occasional variations were sometimes introduced, such as cherry tomatoes or mini and European cucumbers and seasonal options were incorporated such as apples, raisins and walnuts. It was important

to maintain the basic salad vegetables (i.e. leafy greens, tomato, cucumber, carrots, celery, peppers, etc.) but provide enough variation of other materials so that the participants always believed that there was sufficient diversity of options.

7.8: Range of behaviors

One of the most distinguishing features of *Active Engagement* was that at every stage of the program an immense range of participant behavior was established. As is consistent with a heterogeneous population with a tremendous span of sensory disturbances, each member of the class responded to the course progression in unique ways, drawing on individual strengths and hindered by idiosyncratic deficits. For example, while Samar and Sasha were capable of completing the necessary steps to set up their workstation independently, Sasha would complete a step and them wait, needing constant approval or a prompt to move forward to initiate the next component. She would wait quietly and patiently in her chair with her hands folded until either her aide or the researcher prompted her to the next step. None such was needed for Samar who could proceed with minimal direction, unless she was having a behavioral problem and aide intervention was required to redirect her.

Mate, if provided with specific verbal direction, could follow through to completion on each step of the set up, but was heavily reliant on instructions and sometimes even physical guidance. This was true no matter how many times he had completed the procedure and some aspect of behavior management was always required. Andrew was given the same verbal promptings, but was much more hesitant, would often get distracted, and would typically require several refrains of instruction before task

completion. Paul and Katie were completely dependent on their aide to set up; Katie would even stare blankly into space while her aide acquired the materials and made sure that all tools were appropriate.

Here a single skill set -- setting up the workstation -- demonstrates that all of the participants had very different levels of independence, ability, and willingness to participate. These patterns were evident in other areas as well. For example, Ajay and Grant were dependent on the ingredient list as a form of augmentative communication, while Stacey and Samar used it only to browse during salad construction, looking to ensure that they had not missed anything for the week. For some, such as John, the list was confusing, offered too many choices, and was thus not particularly effective as an instrument in salad construction.

7.8.1: Creating individually tailored salads

There is no right way to make a salad. This principle was reinforced continually in *Active Engagement* sessions and the consequence is that many differing kinds of salads were produced. The instructor continually pointed out in class sessions that though everyone started with the same ingredients, each salad that emerged looked – and tasted --

Figure 7-2: Three salads from the same *Active Engagement* Class

completely different. Most salads produced in *Active Engagement* utilized a leafy green vegetable as the primary ingredient, though there was also an occasional chunk salad (See Figure 7-2).

Some participants choose to start salad construction with the first ingredient on the ingredient list (tomato) but others began with a different item for varying reasons. Mushrooms were added to the inventory specifically because Samar requested them and, thus, she always wanted to start her salad there. Others liked to begin their salad with a featured item for the week, or they preferred to start with meat or eggs. Depending on the level of independence, there was a natural flow to each person's progression in the salad production process as they created their own unique rituals and patterns set in the context of the class environment.

The instructor circulated throughout the room creating a social flow between participants; she rarely sat down except to work briefly with individuals one-on-one. It was usually at the beginning of the class session that she would announce any new ingredients, drawing attention to a new topping or dressing that was available if anyone was interested. The response to this type of promotion was varied, depending on the individual's willingness to try anything new and the actual item being offered. Sasha, for example, would try almost anything offered while Rick refused everything new on principle. Some newly introduced ingredients were received by all with enthusiasm (i.e. chicken) while others were met with a tinge of hostility (i.e. broccoli florets).

While acceptance of new items was varied across the class population, in general promotion of items was a highly successful technique for gaining attention and consideration of the new and unusual. After the first few classes, a new ingredient was

usually available each week for participants to include in their salad, if they so chose. New items were chosen by the instructor based on color, texture, or seasonal availability and were circulated through the class so all could view and consider. In her effort to feature these items, the researcher circulated the room using vivid adjectives to describe the taste: "We have avocados today. Some people love the way they taste. Very rich. Very soft. Very green."

Most new or featured options were typically energy dense toppings or new dressings. Once radishes were featured, though they were not well received. Strawberries were accepted by all, but participants wanted to eat them directly rather than dice into their salad. Apples and raisins did quite well in the fall as did pumpkin seeds. The participants were curious about cherry tomatoes, but were indifferent to the mini cucumbers.

Table 7-1 shows the ingredients included for this type of special feature.

Table 7-1: Sample ingredients included for special feature and its acceptability

Fruits	**Vegetables**	**nuts & seeds**	**Other items**
Cherries	Radishes (--)	Walnuts (+++)	Won ton crackers
Strawberries (+++)	Avocado	Pumpkin seeds	Onion crunch
Apples (++)	Mini cucumbers	Raisins	topping
Mandarin oranges	Cherry Tomatoes		3 bean salad
	Whole broccoli (--)		Various dressings
	Bean sprouts (--)		Cheese
	Onions (--)		Bacon bits
			Hard boiled
			eggs(+++)
			Chicken
			breast(+++)

*very well accepted (+++), well accepted (++), not well accepted (--)

Items brought into the classroom for special feature were typically not included on the ingredient list unless they became a favored item and thus warranted a permanent place on the inventory. By far the most popular items added to the ingredient list were protein dense, and were almost unanimously in demand from both aides and participants. Based on repeated requests, the instructor added hard-boiled eggs, turkey bacon bits, as well as cheese to the ingredient list. Chicken breast strips were the last protein item to be included. While the overall response to these items was enthusiastic, the individual reaction was varied. For example, Rick refused both the eggs and chicken, though he had a very strong preference for the cheese. Most liked the egg and chicken, but numerous individuals rejected the bacon bits.

Though the addition of protein to the ingredients available added significantly to the cost and total calories of the salads created, the additions were vital to ensure that participants were enthused about the ongoing progression of the course. Adding more protein-based ingredients certainly moved the salads towards more of a complete meal, but this was not a significant dietary problem since both the Thursday and Friday classes ended at noon and therefore could serve as a lead-in to the lunch hour. As *Active Engagement* is further developed it would be appropriate to advise parents and residential staff that small lunches be packed on salad class days to ensure that over-consumption does not occur.

Group dynamics also played a role in ingredient selection. In general, participants were more likely to try a new item if those around them were also sampling the new item. This worked in reverse as well. On the occasion when whole broccoli florets were

introduced, one individual after the other strongly rejected the item as if a line of dominos. Very few were even willing to taste them.

As the researcher circulated, she would pause where individuals were having problems or interact if a participant was considering their options. For example, if a student was struggling to cut something, the instructor would often address the entire class: "Everyone, Rick needs some help cutting. " Then the group as a whole would be encouraged to sing him through the cutting process ("Back and forth, and back and forth, and back and forth and back and forth").

The instructor would often interact with aides as well if she felt that they were in some way inhibiting the independence of their client. Almost every class session found an aide attempting to complete a task for their client; the instructor would draw attention to this type of behavior and remind the aides that their client was capable of independent work. This problem was in large part resolved early on in the class when it was decided that aides were also welcome to participate and make their own salads during the class. This went a long way towards pushing participants to great independence, given that their aide was distracted with their own salad project and could therefore not hover protectively. Likewise, allowing aides to produce and consume salads also contributed greatly to the overall level of enthusiasm for the course from all stakeholders. In the end this must be acknowledged as one of the most important steps in making the course popular across the entire CSS community.

7.8.2: Change the Texture, Change the Taste

Alongside teaching proper technique two basic principles were re-enforced through the *Active Engagement* curriculum: 1) A salad is a combination of color and texture; and 2) If you change the texture, you change the taste.

Color was addressed directly through ingredient options but texture was more complex and became an area of particular focus with experimentation highly encouraged during class sessions. Several times throughout the course progression, class activities would reinforce the exploration of alternative textures. In moving forward with *Active Engagement*, it might be appropriate to utilize one of these activities as a first-day-of-class endeavor rather than introducing in later classes. The first day of classes is one of the few occasions when attention is naturally focused on the teacher, and thus it is an ideal time to introduce the fundamental concept of texture.

One of the most effective strategies for introducing texture to the class was to employ the Carrot Food Map (Figure 3-2). With the map in front of the participants, the instructor explained "*If you change the texture, you change the taste*." The food map effectively demonstrated this point by illustrating four separate ways to texturize a carrot. Each method required a different tool and created a different product that tasted unique. The participants were asked to prepare each type of carrot texture and then to taste it. What was their favorite texture? Least favorite? Participants were then encouraged to experiment with the different carrot outcomes in their own salad.

The general principles of texture, practiced on a carrot, could then be applied to other aspects of the student's salad. Experimentation in this manner was not only highly encouraged, but continually praised. The instructor made a conscious effort to draw

attention to those individuals who were trying unique preparation options by pointing them out to the entire class.

7.8.3: Portion Control

The process of teaching salad construction to adults with special needs necessitates that portion control be addressed because most salad toppings and dressings are energy dense, i.e. croutons, protein-based items, dressings, nuts, etc. Based on the distinction between energy-dense and nutrient-dense components, participants were allowed unlimited amounts of fruits and vegetables, but toppings and dressing were supplied using a portion control system (see Figure 7-4; Table 7-2). Vegetables were washed and put in colanders on the counter; participants or their aides could come up and obtain what they wanted and as much of it as they liked. Typically servings were as follows:

Table 7-2: Typical portions of vegetable options

VEGETABLE	AMOUNT TYPICALLY TAKEN
Carrots	1 unpeeled carrot. Participant had to peel and prepare as desired.
Peppers (red, yellow or orange)	½ pepper. Participant had to deseed and prepare as desired.
Celery	1 complete stalk. Participant decided which parts to include (i.e. leafs) and how to prepare.
Tomato	½ tomato. Participant had to decide how to prepare.
Cucumbers	½ slicing cucumber. Participant decided whether to peel and/or deseed and how to prepare
Mushrooms	3-4 large mushrooms. Participant had to decide how to prepare
Iceberg Lettuce	1/6 head. Participant had to decide how to prepare (i.e. rip, cut, shred)
Spring Mix	1 large handful
Broccoli	1 large cup shredded
Purple Cabbage	1 large cup shredded

Figure 7-3: Vegetables on the counter, ready for use

Energy dense foods were placed into small paper cups (3 oz.) to visually demonstrate appropriate portion sizes (See Figure 7-4). Class participants were allowed as many different items as they liked, but only one cup of any of specific ingredient. Three ounce cups were used for all items except for broccoli slaw and shredded cabbage which were served in large plastic cups (8 oz.) due to their high nutrient/low calorie makeup. One hard-boiled egg was provided to each participant, if desired, and the serving size for chicken was

Figure 7-4: Energy dense foods using portion control

approximately 2-3 oz. The following items (Table 7-3) were available in portion control sizes:

Table 7-3: Portion control sizes

Item	Details
Seville Oranges	No sugar added; small paper cup.
Cherries	Served in water; no sugar added; small paper cup
Turkey Baco Bits	½ small paper cup
Cheddar Cheese	small paper cup
Croutons	small paper cup
Salad Fixins'	Mix of sunflower, pumpkin seeds, almonds and dried cranberries; small paper cup
Won Ton cracker	small paper cup
Onion crunch topping	small paper cup
3 bean salad	small paper cup
Hard boiled egg	1 egg
Chicken breast	Lightly breaded; 2-3 oz
Salad dressing	small paper cup for all versions

In general participants accepted the portion control system and typically took only one cup of any particular item. During the first several sessions, participants often chose every single ingredient offered simply because it was available. After these first few classes, however, when the exploratory phase was completed, the participants ceased this behavior and, instead, were more selective and chose items based on their personal taste preferences. By the end of the formal lifespan of *Active Engagement* (25 classes) choices were highly individualized though certain items (chicken, eggs) were almost universally selected.

7.9: Communication Methods in the Autism Classroom

The deficiencies in communication experienced across the autism spectrum have been well documented (326-329). Pathologies in verbal speech, grammar, syntax, pragmatics, semantics, and prosody can affect both expressive and receptive language for this population (330). Consequently, it is vital that any instructional environment have a communication strategy in place to overcome these disabilities and to facilitate the learning process.

Due to these severely impaired language capabilities, even simple instructions will be difficult to comprehend and follow for those with autism. The instructor accommodated these deficits during *Active Engagement* sessions with varied communication adjustments addressed both at the class and individual level. Some examples of strategies utilized include:

- literal rather than metaphorical directions;
- limit tasking to one or two steps,
- ask closed rather than open ended questions; and
- limit verbal ingredient offerings to two choices ("this or that")
- offer visual choices (i.e. line up yellow, red or orange peppers in the line of sight for the participant to choose from)

Building positive communication environments for those with autism requires that aides and instructors respond to all behaviors that are appropriate. Thus, when an *Active Engagement* participant expressed themselves – whether verbally or through nonverbal communication – in a manner that was constructive, it was important for the instructor to provide an equally appropriate response in a manner that was

comprehensible to that individual. For example, Grant would typically tap the picture of his favorite topping on the ingredient list so as to indicate that he wanted access. The instructor always acknowledged his request but delayed giving him until the salad was complete: "Thanks for telling me Grant. Let's add the croutons last. What ingredient would you like next?" By redirecting Grant's request she was able to prevent him for over-fixating on one aspect of his salad.

Context driven directions using visuals or hand-over-hand demonstrations were also found to be highly effective for teaching individuals with autism. Non-verbal communication was undertaken with a high affect to help participants grasp and appreciate facial expressions, eye contact and gestures.

A complete evaluation of the varied behavioral and developmental techniques utilized in special education classrooms is beyond the scope of this research. However, it should be noted that of late the emphasis in the classroom has been on individualized approaches that incorporate strengths and weaknesses of the individual, rather than emphasize a whole-class communication strategy. Consequently, the instructor accommodated the communication style to suit the particular person that she was working with at any given time.

While each student required some sort of individualized approach, some methods were found to be efficacious across the entire class. This was particularly true of the use of song during *Active Engagement.*

7.10: Use of Song

There is some belief that the development of music as a system of sound, and beyond simply noise, was related to the development of social bonding in the course of human evolution (331). If that theory were to hold, however, it would imply that those with communication deficits (such as ASD) would be less influenced by music, especially its' emotional components. On the contrary, music therapy has been found to have positive behavioral outcomes for individuals on the spectrum (332-335) though it has not been demonstrated to be effective in the treatment of core symptoms (i.e. reciprocal interaction, etc.) (333).

The understanding of the relationship of music and autism is still in its' infancy and, though incompletely understood, it is now generally accepted that individuals on the spectrum appear to immensely enjoy both listening to and making music and that it is an effective tool in a wide array of interventions (333, 336-338).

While music has been proposed as a potential treatment plan for addressing alexithymia[14] (highly comorbid with autism) (339), it also has far more practical purposes for those on the spectrum. A meta-analysis of therapeutic music programs for those with autism found that use of music increased attention to task, comprehension, social engagement and led to a reduction in anxiety (332). Music has also been tied to improvement in multisensory integration deficits, which are common across the spectrum.

Whatever the reason, the reality is that the use of simple songs is tremendously helpful for establishing joint attention, building social engagement and facilitating multi-

[14] Alexithymia is the difficulty or inability to express, experience or describe an emotional response.

step processing among the autism population. Joint attention, the shared focus that occurs in the typical classroom, is difficult to achieve for those on the spectrum and is one of the reasons that the most effective learning environment for those with ASD is typically one-on-one. Through music, however, the entire autistic classroom is able to share a single frame of focus – the instructor providing instructions.

Music also has the ability to create group rituals that can contribute greatly to social relatedness. Likewise, multi-step processing can also be greatly enhanced with simple songs that effectively walk the participants through the various stages of an activity. In the ability to support all of these vital objectives, songs served as a vital instrument in the *Active Engagement* toolkit.

To be effective in this context, songs had had to be simple, easy to learn, with emphasis on repeated refrains, almost chant-like. Many of the tunes were methodological in that they related to specific skill sets. Other songs promoted social interaction, class ritual or the simple making of salads.

Songs are a form of entertainment but they also work to reinforce specific the development of specific skills such as motor planning, social development and salad production. Different songs were used to address these differing aspects, though all of the songs used held numerous things in common.

1) *Skill Set Songs to reinforce motor planning*

Because the adapted knives utilized in *Active Engagement* rely on a sawing motion for the serrated edge to be effective, it was important that participants be taught the proper motion early in the class progression. Learning a motion, termed "motor mapping", is particularly effective when combined with a simple reinforcing chant. The

single most important song used in *Active Engagement* was intended simply to reinforce this back-and-forth motion related to the use of the knife.

Back and forth and
Back and forth and
Back and forth and
Back and forth.

Conceived by the researcher, this song was likely to be sung 20-25 times in any particular class, either by individuals, dyads or the group as a whole. Sometimes the entire class would sing *Back and Forth*, if the instructor asked everyone to help someone who was struggling to cut an ingredient. On other occasions, this chant would be the product of a single person who was laboring to complete their cutting task. The researcher also noted many occasions when participants could be found singing the tune quietly to themselves as they cut, not as an attempt to gain attention but to – seemingly -- help fuel the motion of the knife.

The systematic use of four refrains regularly repeated ensured that the song was simple, reiterated the basic message and allowed the participant to know and be able to complete the final verse, if the instructor looked to a participant to join in. The same basic melody and format was used to support the concept of what to do with a vegetable when chopping was complete and it was time to move the ingredients to the bowl:

In the bowl and
In the bowl and
In the bowl and
In the bowl

Yet another song with the same structure was a tune that was intended to be draw attention to the idea of exploring texture with vegetables. This simple song encouraged the individual to use the peeler on a carrot (or piece of celery) with lyrics that reinforced the motion of the peeler but also promoted social interaction:

Used during peeling:

One for you and (a peel of carrot is handed to participant)
One for me and (a peel of carrot is handed to researcher)
One for you and (a peel of carrot is handed to participant)
One for me. (a peel of carrot is handed to researcher)

At the appropriate spot in the song, the instructor would take a piece of peeled carrot and eat it so as to model for the participant. One day Francis switched the words around to create a variation on the theme with "One for him and one for her, and one for him and one for her." This alteration was praised by the instructor and Francis' version was used from that point onward in the class.

Other examples of the use of music to reinforce methodological skills in the class included a quick song to assist participants in removing the shells from eggs ("Off with the shell"), and another ditty that supported the stirring of the salad after the dressing had been added ("Mix it Up").

2) Social Songs to build social engagement

Music can reinforce motor planning but it is also a powerful tool for building social engagement through the development of group rituals. For example, the use of the "Name Song" at early *Active Engagement* sessions introduced the participants to one

another and reinforced name recollection. Often one individual would be asked to start the song and they would choose the first name to sing (choosing a person in the room). Each participant would be acknowledged in a refrain of the song with the researcher rotating in the room and standing next to the person who was being serenaded.

Hey Paul, Paul, Paul
Hey Paul, Paul Oh
Hey Paul, Paul, Paul
Hey Paul, Paul Oh.

Like the other songs utilized in *Active Engagement*, the "name song" has few words, a simple refrain, and the basic concept is repeated multiple times. Consequently, it could be easily internalized by participants and aides alike and could also be readily adapted to acknowledge every participant or visitor in the classroom. This song became renowned in and outside of the classroom; as the researcher walked down the CSS hallways various staff would sing it to her. ditty, it tends to stay with you.

3) *Salad Processing Songs*

Songs about making a salad emphasized course goals as well as the individual nature of salad construction. The most important song in this category was "*Let's all make a salad*", which was intended to support the concept that everyone's salad was unique. Sung to the tune of "The More We Get Together":

Let's all make a salad, a salad, a salad
Let's all make a salad, and start with a _____
We'll add _____
And _____
And _____
And _____
Let's all make a salad and end with some _____.

Sometimes this song would be sung with differing participants supplying the missing parts; on other occasions one participant would do the entire song themselves. Key to this tune, as with the others, is that it is easily learned so almost all those who were verbal could participate if they chose.

Songs were most likely the most popular aspect of the *Active Engagement* experience. Nonverbal individuals, such as Ajay and Paul, were alert during the songs indicating that recognized and appreciated the music, particularly when they were being serenaded with the "name song". While Samar always wanted to lead songs, Sasha or Brian would only quietly sing the tunes to themselves, their mouths moving but their voices barely heard. Francis developed over the course of many weeks into a skillful soloist who could not only sing the *Active Engagement* songs but actually invented new ones.

7.11: Interaction among the Participants of Active Engagement

Because of the sensory abnormalities experienced by this population, joint attention is not an effective teaching technique for this population. Consequently, *Active Engagement* is designed to place the learning environment directly in front of the individual. All instruction takes place at the workstation with hands-on tasks and experimentation and without the teacher as the dominant educational focus.

Despite the fact that each individual is positioned to be an independent unit, it is still possible to create a learning environment incorporating social interaction, both between participants and with the instructor. As discussed above, one of the ways that

this was achieved was through the use of song. Song helped to create a strong group ethos as well as class ritual that participants could share.

But song was not the only force at work as it quickly became apparent that peer observation, behavior modeling and imitation were powerful influences in the *Active Engagement* classroom. For example, on one occasion, several individuals were invited into the class to participate as guests at a "salad party." One of the guests, Andrew, made an unusually attractive salad out of iceberg lettuce. Up until that point the participants had predominantly used spring mix or romaine (though iceberg was always available). Everyone noted Andrew's salad, which the instructor had pointed out, and how appealing that it looked – it simply looked very different that the salads that had been seen to that point. Soon everyone was demanding iceberg lettuce and, for a period, it became the most popular of the leafy green options.

Anecdotes such as this demonstrate the powerful effect of social forces in the *Active Engagement* classroom, despite the social deficits inherent to autism. Noting this, and hoping to harness this phenomenon, the instructor began to point out with increasing frequency to the rest of the class unique aspects of the individual salads – drawing particular attention to variations and trends. It was in this way that other socially-driven trends developed such as the rising demand for combining ranch and honey-mustard dressings to create a new, tangy hybrid dressing, which was very popular in the class for a period.

Social forces also worked against the group on occasion. When individuals exhibited challenging behaviors, it was sometimes difficult for neighboring participants to carry on with their own work. One day Paul was struggling, clearly upset, and was

trying to leave the classroom though his aide refused to allow him to go. Rick became upset by the noise and Paul's aggression and became so agitated himself that, ultimately, his aide escorted Rick out of the classroom. In general this type of negative social force was dealt with during the seating process, by ensuring that those individuals who might likely be countervailing influences be separated.

7.12: Progression of the four primary skill sets

The conceptual framework introduced in Chapter 5 provides an overarching structure for *Active Engagement* rather than any specific nutritional goal. In doing so it is acknowledged that the development of generalized cooking skills will enhance the variety of food consumption and, in the context of salads, create an environment conducive to the consumption of increased fruits and vegetables, if only in the increased access. The conceptual framework is guided by the work of Hodge et al.(299) that strives for the development of life skills amid four motivational climates. These include autonomy (individual production of salads), self-efficacy (competence in salad preparation skills), social-relatedness (participation in the class), and preference (consumption of the product).

Hodge et al. contend that if an environment can be met that satisfies the requirements of these four domains, learning can be optimized. Consequently, it is important for *Active Engagement* to address and satisfy the requirements of these particular skill sets.

7.12.1: Self-autonomy

Figure 7-5: Sticker used for Salad Assembly

Cooking instruction is common in special needs programs, though typically the subject is taught as a communal activity with one individual having one small and distinct job in the larger group production. The salads produced in *Active Engagement*, however, are not constructed in this manner. Instead, each salad is the product of an individual and their unique preferences and abilities.

The concept of self-autonomy was reinforced in every *Active Engagement* class in numerous ways. The instructor would, for example, talk about "Rick's salad" or "Samar's salad." She also made a habit of asking participants as they came or entered the classroom who made the best salad in the world. Typically students would indicate themselves and those who were nonverbal would often pat their chest as an answer. One day, however, Francis– who had been participating very reluctantly in the class to that

point – was asked who makes the best salad in the world, to which he responded "Someone else."

But self-autonomy was also promoted on a larger stage with two assemblies held for the CSS community in the common area during lunch. Veterans of the class prepared salads that were served out to those who attended. To promote self-autonomy each participant wore a sticker (Figure 7-5) identifying themselves as the best salad maker in the world. It was noted by the instructor that the participants very much enjoyed this event, took great pride in displaying their salads and in sharing them with their peers. The promotion of these assemblies utilized materials highlighting individual contributions and the students enjoyed seeing themselves on the posters distributed.

Autonomy is also referenced in the decision making that *Active Engagement* requires, in the very process of choosing and determining individual outcome. Here, the program offered an open-ended approach to teach cooking that allowed each participant o follow their preference and create something that was very much their own. Thus, the creation of an environment that supported self-autonomy was satisfied in *Active Engagement.*

7.12.2: Self-efficacy

Self-efficacy references competence, or the ability to carry out the production of an individualized salad. Once learned, self-efficacy requires that participants have the ongoing ability to exercise and express these capacities. From the outside, *Active Engagement* may appear to be a rather simple curriculum: each week the student makes a salad. But because the outcome objectives were stable over time, the participants had the opportunity to gain mastery over the skills involved in preparing a salad. The sheer

repetition of repeatedly making a salad is a strength of the program and designed explicitly for a population that thrives with routine and struggles with change and the unpredictable.

In this capacity *Active Engagement* was successful in creating an environment where individuals were given the necessary support and opportunity to master the technical requirements of a pre-cooking curriculum.

The range of self-efficacy development during the progression of *Active Engagement* found most participants making progress. Some individuals slowly built to proficiency in chopping and cutting (i.e., Rick) while others seemed to make no progress and then suddenly leapt to competence (Katie). Johannes found competence quickly though his slow and deliberate work mean that he was always the last to finish.

7.12.3: Social Relatedness

The need for social relatedness is built upon the innate human desire for a sense of belonging, within the larger community as well as amongst peers. *Active Engagement* was socially conceived and specifically designed for participants to enhance social skills. Coming together as a group on a weekly basis and participating in the group rituals creates community (in anthropological terms, culture).

Of all the deficits of autism, social relations are one of the most significant. Consequently, the process of participating in the class activities allows individuals to commit to both making a salad as well as belonging to a group. Through songs, ritual, assemblies and habits *Active Engagement* successfully created an environment in which social support contributed to psychological wellbeing and allowed for optimal learning of pre-cooking skills.

7.12.4: Preference

Because *Preference* plays such a large role in the framework of consumption in general (and fruit and vegetable consumption in particular) it has been incorporated as a fourth component, though it is not typically included in life skills programs. In some ways the most challenging aspect for a group of individuals with notorious food selectivity, preference is also the most rewarding in terms of obtaining feedback. Those with autism may reject foods forcefully, but they will reject – they are not indifferent to the foodstuffs that are placed before them.

Preference is also one the most variable outcomes in Active Engagement. Some individuals (i.e., Ajay, Samar) were willing to consume their salads from the first class. Others (i.e. Stacey, John) were slow converts. One student, Johannes, entered the class on the first day and ate his entire salad, despite the fact that the researcher had been warned that he was a particularly selective eater. Consequently, it is clear that the level of access and exposure necessary to encourage actual consumption of the salad was quite distinct for each participant.

When addressing the issue of dietary variety in neurotypical children, nutritionists typically rely on the idea that it takes at least ten exposures before a child might be willing to try something new (340). Guidelines such as these have to be thrown out when working with individuals with autism. Katie, for example, had made tremendous gains in acquiring cutting skills and participating independently in the class. She had not, however, been willing to partake of her salad and it was only late in the class progression that she had finally broken through and began to fully consume her salad, rather than simply pick out her favorite ingredients from the bowl.

In the final analysis tremendous gains were made across the entire class, for all of the students, though the path to behavior change and the skill set involved was unique in each particular case. Lee was never willing to consumer the salad that he constructed; his progress was likely partially hindered by the fact that his lunchbox was stuffed with an entire box of cookies each day. Consequently, Lee would reject the salad in favor of his reliance on the processed carbohydrates waiting for him at lunchtime. Rick never came to consume more than a few ingredients thought he became quite competent at chopping and cutting. Several individuals, such as Caroline and Francis would construct small salads with five or six ingredients, which have to be seen as successes. Others (Johannes and Yvonne) would produce massive salads and eat every single bite themselves.

7.13: Typical Problems in the Active Engagement Classroom

Problems are inevitable in any educational setting and in *Active Engagement* such issues ranged from the mundane (running out of an ingredient) to the dramatic (a participant having a behavioral meltdown and being escorted from the room). The most common problems that arose during *Active Engagement* included the following:

7.13.1: Motor Delays

The first weeks of the course were devoted to learning the technical aspects of salad making, particularly cutting, chopping, grating, and peeling. By the fifth class only a handful of individuals were still struggling significantly with this skill. Typically most individuals can learn to cut with an adapted knife, and then – ultimately -- progress to real cutlery. When there are fine or gross motor problems, however, there are a range of

options that can be utilized (see Table 5-1). The challenge is determining the best approach for the individual and their unique skills and deficits.

Table 7-4: Options for Learning to Chop/Cut

Rip or Tear:
- ✓ If the individual has low muscle tone or difficulty with coordination of right and left hands, it is often best to work without a knife.
- ✓ Lettuce and peppers can be torn or ripped; emphasis can be placed on size of fragments.
- ✓ As the course progresses, this technique can also be used with individuals who have already mastered adapted knives as a useful approach to introduce variety and change into the curriculum.
- ✓ Scissors can also be used on lettuce.

Adapted Knife with Stabilizer:
- ✓ Individuals who struggle with right/left hand coordination but have reasonable grip strength, might do well with an adaptive knife.
- ✓ A fork is used to stabilize the object being cut while the knife cuts through the material.

Adapted Knife with Proprioceptive Input:
- ✓ Individuals who have adequate right/left hand coordination but have issues with grip strength are well suited to use the adapted knife along with proprioceptive input.
- ✓ This can come in the form of mild pressure on the cutting hand or can involve the use of wrist weights.

Adapted Knife:
- ✓ Using the adapted knife on its own works well for the majority of individuals.
- ✓ This works well to teach how to position vegetables without "cutting" fingers.
- ✓ It is also excellent for teaching the back/forth motion needed as the serrated edge of these plastic knives are not particularly efficient with only a downward motion.
- ✓ The ergonomic handle is designed to be held by children ages 4 years and up and conformed to the safety requirements of Toy Safety Standard ASTM F963 for minimal risk.
- ✓ Despite the fact that they are regulated as toys, such knives are utilizable as functional tools in a kitchen setting.

Roller Knife:
- ✓ This tool allows for continuous cutting and works well with lettuce, peppers, and celery.
- ✓ Though the motion is easy to learn, the positioning hand is vulnerable to the blade.

Food Cutter and Popper:
- ✓ This popper chops into small even pieces and pushes the uniform pieces through a sieve.
- ✓ This tool requires little fine motor control but does need physical strength.
- ✓ Not particularly useful for chunky vegetables.

Cutting Knife with Cut-Resistant Glove:
- ✓ Individuals who have mastered the adapted knife can proceed to cutlery; it is wise to use a safety glove with wire mesh to ensure that the transition is a safe one.
- ✓ The glove protects the stabilizing hand only and safety remains a priority for other components.

Independent Knife Use:
- ✓ It is often best to begin with dull knives, or knives without blades (butter knives) before transitioning to authentic cutlery.

Adapted Knife 	**Rocking T Knife** 
Roller Knife 	**Food Popper** 
Cut Resistant Glove 	

Figure 7-6: Options for adaptive cutting tools

Several weeks into the class it was apparent that Joseph, a young man with a tremendous range of motor planning issues as well as ADHD, was still struggling to work with the adapted knife. Joseph was unable to harness enough power to cut and also had deficits in dual coordination of the left and right hands. Based on the range of options, and after consultation with the CSS occupational therapist, it was decided to try a rocking T knife (See Figure 7-6; Table 7-4). It was discovered that, if Joseph stood, he could transmit power into the curving blade of this knife and thus provide enough strength to cut vegetables. It was also determined that Joseph benefited from using tools (such as a grater or peeler) with a wide handle that allowed for a stronger grip.

Most of the problems that other participants experienced with learning proper technique related to the back and forth motion that the knife required. The instinct when working with a knife is to press down, but the adapted knife requires a sawing motion to be effective. This issue was primarily addressed through song (see above for "Back and Forth" song). Another important aspect of learning the proper cutting technique was ensuring that aides took a step back so that their charges would actually try to use the knives independently, rather than rely on hand-over-hand guidance. Once the aide ceased to provide assistance, the participants quickly started investing in the process and began to cut for themselves.

One of the most physically handicapped individuals, Johannes, was actually one of the harder workers. He mastered the motion of cutting with the adapted knife, but it took him almost 30 minutes to complete the necessary chopping needed to produce a salad. If the instructor or aide tried to assist him or to speed he process along, he would wave them away. Slowly, but methodically, he worked his way through his preferred ingredients.

When done, he then set about eating the entire salad, which could also take additional 30 minutes. Because of epilepsy, he would occasionally have a seizure during class and would then be quietly pulled away from the table until he returned to consciousness. When he was sufficiently lucid some time later, he would simply take up where he had stopped.

7.13.2: Challenging Behaviors

Autism is defined in many ways by its challenging behaviors, those actions that are extreme in frequency, duration or the danger in which they put the individual (330). On the spectrum these behaviors are widespread and highly variable and it is vital to appreciate when and how a behavior can be transitioned into something constructive. The instructor quickly had to learn when to step aside and let the aide take over, usually by removing the individual from the class or implementing a behavior plan.

Several individuals with challenging behaviors were given private classes, so as to avoid negatively affecting other participants. These one-on-one classes were designed to mimic the larger class, but the individual was provided instruction in a room with only the instructor and their aide. This approach lacked the social component of the larger classes but freed the researcher to provide more direct assistance and interaction.

Three individuals were given individualized instruction for varying lengths of time. One individual, Grant, suffered from severe pica that was life threatening if not given careful supervision, so had to have more intensive attention than was typically given in the *Active Engagement* classroom. The instructor's work with Grant was highly productive, however, and after a short while the two were able to undertake several simple cooking projects in addition to salad production. When Grant's instruction ceased

in late May, 2014 due to a change in programs, he had had made significant progress in an individualized course set-up.

Another individual, Russell, very severely disabled and nonverbal, actually enjoyed eating salads before starting the class. His educational goals included having him prepare his own salads but his schedule was not sufficiently flexible for him to join one of the on-going *Active Engagement* classes. Consequently, one-on-one instruction was begun and Richard made fast progress on his salad-making goals.

The last individual who received a private class was Julian, who had many challenging behaviors with the most pronounced being extreme anxiety. At the second meeting, Julian was so apprehensive that his aide had to take him for a drive, one of the few techniques that helped to calm him down. Seeing this, the instructor suggested she join him for an impromptu class in the car. With the aide driving them slowly around the block over and over, she and Julian prepared a small salad in the back of a CSS van.

In sum, while the social component of *Active Engagement* is one of its strengths, the use of one-on-one instruction offer the opportunity to incorporate individuals with challenging behaviors that could not typically participate. The dimensions of the curriculum are altered, but not the outcomes.

7.13.3: Behavior Rigidity

Behavior rigidity is characteristic of many psychopathologies, including autism. In the difficulty in transitioning between activities, environments or even internal aspects of the same task, behavior rigidity is often reflective of deficits in self-regulation. Dealing with this phenomenon in educational environments can require the use of concrete organizers (such as the ingredient list), verbal assurances ("First this, then this"),

peer modeling (visual cues from other participants) and reinforcement of self-autonomy ("Who makes the best salad in the world? That's right, you do."). There is no right approach but, as with everything in the autism classroom, a toolkit is needed with multiple options.

Behavior rigidity was manifested in the *Active Engagement* classroom in numerous ways. Participants often wanted to recreate the exact same class experience repeatedly and it was the instructor's responsibility to reassure the students that change (whether in songs, ingredients, texture, or salad outcomes) could be tolerated and even enjoyed.

Self-efficacy, self-autonomy, and social-relatedness were often quick to develop over the course of the class progression, and yet preference for certain ingredients often failed to develop. Each person had to be dealt with individually, with a different approach that brought them to the point of bringing a cucumber or celery or tomato to their lips. The only techniques that worked across the board were patience and an acceptance of the individual's right to refuse.

On several occasions the researcher utilized the Carrot Food Map for those who had participated in class but had not broken through to actual consumption of their salad. Working with the individual one-on-one, the researcher would help the participant prepare the carrot with four distinct textures, reminding them that if the texture was altered, the taste would be changed as well. Often this simple activity, done one-on-one, would be enough to get them invested in the process.

Another approach to addressing the issue of preference was to play the "dipping game." Working one-on-one with the participant, the instructor would line up three small cups of dressing, all of different colors. The student would chop vegetables and then be

asked to dip the vegetable pieces in any of the three cups. If the dressing cups were distinctive enough in color, the participant would often be sufficiently curious to taste the vegetable-dip combination. One several occasions, this activity worked perfectly to help transition a participant to enhanced preference.

Francis had been very reluctant to participate in the class on all levels. His apathy was partially driven by his aide who felt that the noisy, chaotic atmosphere in the class was detrimental to Francis. Thus, Francis knew that if he resisted during class, his aide would ultimately decide to take him out of the room early. And, indeed, this happened at many of the early classes.

The first priority became simply keeping Francis in the room in the hope that he would come to enjoy the class process. Several different roles were developed for Francis. The final – and most successful – approach was to provide Francis with a "customer" each week. The customer would take the ingredient list as a menu and place an order for a salad based upon preference. Working off of this list, Francis would prepare this salad and present the completed project to his customer.

Francis could not abandon the project in the middle (as he had been doing when making his own salad) and had to follow-through to the end so that he could present the salad to his customer. Moreover, making a salad repeatedly required the acquisition of the important skills of cutting, chopping, grating and shredding. This was a highly effective approach and it was not long before Francis became very efficient at making salads and was even particularly proud of his salads, which were highly praised by customers. Francis was now participating in the class activities – particularly the songs – and seemed to really enjoy the class.

After some months of working with "customers" it was decided that Francis had enough separate ingredients that he was willing to consume (i.e., chicken, cheese, eggs, carrots, cucumbers). Because of this it was hypothesized that Francis might be ready to use these "acceptable" items to make his own salad, which he did indeed do. This was a big breakthrough as, for the first time, Francis produced a salad and acknowledged that he was willing to partake. It is hoped that this will be a launching point for Francis to experience continued gains.

7.13.4: Nonsynchronous Class progression

Because the participants worked at their own speed, it was possible for one individual to begin eating while others were just beginning. Thus, while there was a social ethos, there was often no communal sense of a meal eaten together. Some individuals had to dash out of the room quickly to maintain their schedule, while others remained in the room to partake lunch with other CSS clients who began to filter into the room.

The end of the class was a chaotic time with each individual attempting to complete their tasks but at different stages of the process. In the next generation of the class, it would be beneficial to put the class in an environment where some of this lunch chaos can be mitigated and participants could all join in a shared meal.

7.13.5: Attendance

One factor of *Active Engagement* that was both vital to a successful outcome and which was also measurable was attendance. Attendance was an important component in

individual progress in the course but was beyond the control of the instructor or the participant and was most typically affected by vocational placement. Often there would be no explanation for the absence of an individual; inquiries would reveal that the individual was sick, on vacation, had a brief job assignment etc. Having a central communication system that the instructor can use for interacting with staff and aides regarding schedules will be vital if *Active Engagement* is to move forward and grow.

Brian made tremendous progress during his time in in *Active Engagement*, hindered only by his many absences from class. Every time he would have a productive class where he demonstrated improvement in self-efficacy, self-autonomy, social relatedness or preference, an absence would cause the gains to dissipate. The return to class would reveal that Brian had not completely consolidated gains made in previous sessions.

7.14: Conclusion

This examination of the *Active Engagement* trajectory confirms that qualitative analysis using ethnographic techniques is a powerful tool for gaining insight into the behavior of individuals on the autism spectrum (276). Data was collected in via unstructured observation and interpreted through a variety of themes running throughout the program. In producing this ethnography the researcher had two goals. First, there was intent to demonstrate that, though everyone who participated was affected, each person did not experience the intervention in the same way. Second, as an initial exploration of a health promotion, the author strived to make sense of the means by

which *Active Engagement* was, or was not, successful at engaging these individuals in the task of learning basic food preparation skills, specifically chopping, cutting and grating.

Because of the lengthy duration of *Active Engagement (*25 weeks) and the relatively unlimited budget for materials provided by CSS, the researcher had the enviable opportunity to test many different approaches as well as build a significant collection of methods, tools and activities for teaching initial food preparation.[15] As the program moves forward, it will be necessary to determine how *Active Engagement* can be more systematically evaluated. Perhaps this should involve invoking the standard criterion of formal evaluative processes (341); or, the use of informal methods for evaluating a smaller scale intervention.

One of the limitations of this ethnography is the researcher had two dual (and sometimes opposing) responsibilities: interacting/intervening in an attempt to alter behavior, and simply observing to see how participants would respond independently. The researcher took an activist role in the *Active Engagement* classroom, but there were times when these dual responsibilities were contradictory.

Another limitation that should be addressed in the next iteration of the program is to incorporate a more formalized interview process with aides. Conversations with parents had been a particularly valuable source of information, resulting in tremendous amounts of pertinent data. Though aides were informally questioned as to their thoughts and opinions, a more structured approach would shed tremendous insight into the class processes and contribute to an even more vigorous process of data triangulation.

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[15] For a view of the various tools utilized in *Active Engagement*, visit www.AutismCooks.com, the supporting web site for the program.

Whether informal or structured, future analysis of the effectiveness of the program will require ways to isolate and possibly calculate measurable aspects of *Active Engagement.* Program evaluation is, however, beyond the scope of this chapter or this thesis.

Chapter 8: What Happened to Paul? Manifestation of Abnormal Pain Response for Individuals with ASD

> "In a quest, an inciting incident (i.e., trouble) sets a protagonist's life out of balance"(289).

8.1: Introduction

What follows is an open-ended account of Paul, one of the students participating in *Active Engagement.* During the course of the school year, Paul experienced a traumatic accident that fundamentally changed his behavior and his educational trajectory. It is the researcher's belief that the unraveling of Paul's participation and the challenging behaviors that erupted were a response, filtered through sensory abnormalities, to the pain and stress of his accident.

Though Paul was believed by those around him to have experienced no pain from the accident, the available evidence can be arranged and interpreted so as to indicate that the physiological and related stress of the event caused him tremendous anguish. He expressed this in the only means available to him: self-injurious and challenging behaviors, excessive day-time sleeping, reduction of appetite and weight loss and a rejection of objects and activities that he had previously enjoyed, including *Active Engagement.*

8.1.1: The Pain Response in Autism

At one time many researchers and practitioners believed that individuals with autism did not feel pain (342), a conclusion based on anecdotal accounts (from parents, health care professionals and others) and limited clinical observations. Moreover, measures of pain for such conclusions were inconsistently applied and not validated. While some individuals on the spectrum were noted as hyposensitive, others complicated this picture by proving hypersensitive to pain stimuli. Moreover, there was also a segment of the autism population that presented as simultaneously both hypo and hypersensitive (343). Consequently, a single individual could appear to experience no pain from a broken leg but could find the sensation of someone hugging them as excruciatingly painful. These variations of an abnormal pain response support the underlying understanding of autism as one of pronounced sensory irregularities and contribute to concerns about providing adequate health care to individuals who present symptoms through non-verbal forms of communication.

Recently researchers who have analyzed the phenomenon of reduced pain sensation in some individuals on the spectrum contend that it is not the consequence of an authentic analgesia. Instead, it is suggested that atypical sensory processing and stimulus over-selectivity, well documented in other domains for this population, simply spill over into pain pathways and pain amplification mechanisms. The consequence is not a reduction in pain sensation, but a different expression of pain, determined by that individual's particular communicative, cognitive, or physiological deficits (344). Controlled laboratory studies (345) as well as literature reviews (342) of the pain

response for those on the spectrum verify this conclusion and make a strong case for the development of new and more appropriate pain monitoring systems.

Given new concerns regarding the pain response as a masking mechanism for underlying problems including illness, pain or discomfort (140, 346), health care professionals (including nutritionists/RDs) need to become more observant as to behavior that could be suggestive of pain or discomfort of GI or other conditions (344, 347-349). It has been hypothesized that many maladaptive behavior changes can either signal pain or can serve as a counter-irritation to mask or cope with such (347). Understanding the unique trajectory and communicative ability of the individual is vital to determining masking behaviors and developing an authentic dialogue with parents and caregivers is essential.

It is too easy for healthcare professionals or caregivers to ignore behavioral or mood problems, or to dismiss them as a manifestation of the ASD rather than as a clinical sign (350, 351). A recently published literature review referencing pain on the spectrum found that high functioning individuals, who were capable of effectively responding to questions about pain levels, were often indifferent to pain. Yet, when probed as to the issue of comfort ("How uncomfortable are you?), were highly responsive to questions. Exposure to pain among the subjects often led to perseveration and it was hypothesized by the authors that treatment of perseveration was the most effective means for addressing suffering, rather than medicating for pain reduction, though this hypothesis remains to be tested.

Aside from the physiological response to pain, the communication of discomfort or pain appears to be hindered by a number of pathologies. Both verbal and nonverbal

communication impairments can contribute, as can difficulty in locating the painful area on the body, or establishing its cause. Other problems correlated to deficits in sensory, emotional or cognitive domains likely contribute, as do problems in providing socially appropriate responses to discomfort.

This emerging issue for individuals on the spectrum will require the development of new, alternative pain assessment tools that allow this population an effective means of communicating their physical status. It is equally vital that those who are being treated are prepared for this process and desensitization preparation will likely be necessary (352, 353) to help them accommodate to the physical and communicative demands of medical care.

The extended interview with Paul's father addressed herein demonstrates how the pain response was manifested in one young man on the spectrum and helps to provide meaning to the events surrounding Paul's accident. Using the combined impressions of Paul's father with the researchers observations of his behavior will help to effectively shape the story and answer the question, "What happened to Paul?"

8.2: Methodology and Design

Paul cannot tell his own story or answer the question "What happened?" How then to endow his behaviors with meaning, to make sense of his actions both before and after the accident? Using Paul's story as the basis for an observational case study provides an over-due examination of the pain response for those on the spectrum. While a case study provides the means for the examination of an individual experience, it is through qualitative analysis that Paul can be given a voice and his story generalized.

A qualitative analysis using ethnographic techniques (i.e., fieldwork, participant observation, structured interviews) has been defined elsewhere as an appropriate and effective tool for gaining insight into the behavior of individuals with developmental, linguistic, and perceptual limitations (276). Such approaches allow the researcher to move beyond the challenges of a non-communicative subject by viewing behavior as a response in and of itself. That is, each individual *expresses* as a result of interactions with others and a material world. The enacting of preferences (301) can be noted and becomes a powerful form of communication that can be read and interpreted.

In this essay qualitative analysis is used to ask and answer the question: "What happened to Paul?" Data collection consisted of field notes collected by the researcher as a participant observer in *Active Engagement.* Notes, based on observations, were composed by the researcher and collected on a weekly basis. Other information available included an extended interview with Paul's father, Marty, as to his eating history and consumption patterns as well as all diagnoses, medications and comorbidities. Commentary from aides and staff, photos and video complete this data collection.

The information collected regarding Paul's life and behavioral patterns was obtained in one extended interview with Paul's father, who graciously sat with the researcher in his home. The unstructured observational data collected during *Active Engagement* spanned a period of almost 8 months, as did the photos and videotape. Aide observations were collected casually with the researcher during breaks in classroom activities.

All names and identifiers of people involved in this case study have been changed to ensure anonymity. As with all of the individuals who participated in *Active*

Engagement, approval was obtained from Paul's parents and the approval process was sanctioned by the UMD Institutional Review Board.

8.3: Data Analysis

The collected raw data was arranged so as to emphasize transformational processes at work rather than simply procedural or chronological markers. Paul's journey was marked by both progression and regression and is best interpreted by filtering through a variety of biomedical resources on the nature of pain in the ASD population (discussed above) and an examination of Paul's changing behavior during the period under analysis.

Qualitative analysis is inductive and assessment emerges from the data to provide a considered understanding of a particular case or circumstance (297). The significance of data is often not even immediately apparent to the researcher. It is only later -- with the aid of background research, observation, instinct or inspiration -- that meaningful patterns begin to emerge. From seemingly random events, a cogent narrative develops (321). This process is highly iterative and, consequently, the data can be reconfigured – rearranged – to form alternative conclusions. When done properly, however, qualitative analysis is a powerful tool for explaining the inexplicable – in this case the lived experience of those who cannot relate their own story.

Following Yin (295), each case study practitioner has their own means of approaching the data to recover patterns. Meaningful patterns cannot be forced and must be inherent in the material collected. For this study, the researcher teased the data to arrive at a theoretical perspective that matched the surrounding research as well as her

own understanding of the situation. This process built towards an interpretive conclusion that was capable of being contrasted with rival or differing explanations of the data.

8.3.1: Analytic Frame

The analytic frame attempts to make explicit the links between the concepts under investigation (autonomy, efficacy, relatedness and preference) with the inferences drawn regarding the pain response to assess construct validity. The emerging research that addresses the pain response in the face of hypo and hypersensitive modalities (discussed above) served as one of the primary resources for the analytic framework though the researcher alternated this newly developing understanding with raw observational data on Paul's behavior and ethnographic accounts of other individuals on the spectrum and their response to stimuli (pain and otherwise). Taken together these resources expose the transformative processes at work – a particularly powerful technique for individuals who are non-verbal or minimally communicative.

8.3.2: Analytic Process

The analytic processing of data involved numerous steps. First, the researcher reviewed the field notes from each class. Events, defined as significant moments for Paul during differing sessions, were noted and explored. To clarify issues that arose through this technique, the researcher would often question aides, staff, or Paul's father as to their memory of the event. Next, the researcher transcribed the substance of the extended interview with Paul's father and searched for patterns based on her background knowledge and practical experience. Additional research was conducted on various aspects of the father's commentary and the questions that he raised regarding the

trajectory of Paul's development. Likewise, the events of Paul's accident were linked with the field notes to find the overlap and the nature of the changes in his behavior following the accident. Lastly, both achievements and setbacks for Paul were broken down and analyzed for the significant details. What methods and techniques allowed Paul to make progress? What aspects hindered Paul? These were all questions that the researcher sought to answer through data analysis.

8.4: The World of Paul

> "A credible, authoritative, authentic, and trustworthy voice engages the reader through rich description, thoughtful sequencing, appropriate use of quotes, and contextual clarity so that the reader joins the inquirer in the search for meaning"(265).

Paul is completely nonverbal. According to his father, his only spoken word is "ba-ba" which stands in for "bye-bye". However, his father has not heard this sound from Paul in a long time and is unsure if Paul is still capable of saying it. In the household setting, Paul uses the Picture Exchange Communication System (PECS),[16] which is spread throughout the house, to express his wants and needs. The things that Paul will ask for with PECs are concrete; he never uses his augmentative communication to express abstract thoughts or to discuss his physical or emotional status. Consequently, his story must be told by others; in this case his father and the researcher.

Paul, an only child, is 20 years old and lives at home with his parents. He is in the final year of his formal education and attends the small school that CSS has recently

[16] PECS is an augmentative communication package for ASD and DD that focuses on the initiation component of communication and attempts to allow individuals to learn the rhythms of communication.

opened on their campus. Paul has a dedicated aide at all times to assist and coach him through his schedule and educational tasks and to prevent him from self-injury.

Paul's father is a retired lawyer who worked in the federal government and Paul's mother continues to work full time. His father's major preoccupation, now that he is no longer working is to deal with the unending logistics of having a severely disabled adult child. Scattered across the living room table are forms, files and documents that form the paper trail of his son's disability. Paul's father, Marty, is uniquely situated as the only father interviewed for this project; all of the other parents interviewed were mothers.

Sitting in the living room of their comfortable suburban home, Marty talked at length about his son's developmental history. Paul was diagnosed with Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS) as well as static encephalopathy before his second birthday; he is profoundly disabled in language, cognition, and in social interaction. PDD-NOS was formerly considered as an autism subtype that was considered atypical from classic autism. It is now included under the broader umbrella term of ASD. Static encephalopathy indicates permanent and unchanging brain damage.

Marty tells the researcher that he has a video of Paul when he was 18 months old. In this video, according to his father, Paul can be seen displaying typical infant behavior as well as beginning speech patterns that were all progressively normal. For whatever reason, some event occurred between his 18th and 21st months of life that caused Paul to regress. During this short window of time Paul not only stopped acquiring language and cognitive skills, he lost all of the previously acquired abilities. When medical

professionals were consulted at 22 months, a neurologist found Paul had idiopathic shrinkage of the hippocampus that resulted in his dual diagnoses.

Marty glosses over the psychological impact for his family of this event, perhaps because the diagnosis is so far in the past, but lingers on the cause of his son's condition. Marty is highly educated, well read, and wary of attributing Paul's pathology directly to the measles, mumps and rubella (MMR) vaccine, knowing well the heated debate around this issue in the autism community. A 1998 paper (354), which was retracted by most of the authors, suggested a possible relationship between the MMR vaccine and autism. The backlash was heated and visceral and left many parents of ASD children feeling that their stories were being brushed over in a wave of public health concerns about reduced vaccination rates. Lost amidst the heated discourse were several thoughtful studies in response to the original article that did effectively demonstrate that the vaccine is not, at the very least, the primary cause of autism (355, 356). Marty notes how the events of Paul's regression coincide perfectly with the timing of his MMR vaccine, but goes no further.

An estimate of individuals on the spectrum who experience the regressive form of autism, as Paul did, ranges from 15% to 47% (357). This wide range is related to the fact that many people who believe that their child regressed actually missed manifest signs of ASD and confused early language with simple echolalia.[17] Idiopathic regression is seen to be specific to autism, and marks it as unique from the other developmental disorders.

[17] Echolalia, a common communication disruption in autism, is the repetition of words, phrases or vocalizations. Some individuals repeat the same short phrase; others will repeat extended scripts.

Though he has never been given a formal diagnosis of epilepsy, Paul also experiences grand mal seizures.[18] After these episodes, which are rare but regular according to Marty, Paul usually sleeps for an extended period of recovery. Paul's other formal diagnoses include ID, motor planning and fine motor disabilities. His father indicates that there are likely other psychiatric conditions that remain undiagnosed including obsessive-compulsive disorder (OCD) and anxiety.

Clinical diagnoses aside, Marty believes that the essence of Paul's disability is that "he just really doesn't understand language" and, consequently, can only interact at a very minimal level. Marty and his wife's goal for Paul is to make him as comfortable as possible in the coming years and to ensure that he does not have excessive anxiety. The world is a very stressful place for Paul; removing that stress takes up a good deal of Marty's time and energies. While pharmacology plays a role in anxiety reduction, the use of schedules, rituals and routine are also tremendously helpful in treatment of anxiety for individuals with ASD.

At 5;9" and 235 pounds (as reported by his father), Paul is very heavy with a BMI of 34.7, close to the cutoff for morbid obesity. His father reports that Paul has recently lost weight (approximately 10 pounds) but is unsure whether to attribute this to recent changes in his seizure medicine or the accident, which resulted in a change in all of the familiar patterns and rituals for Paul. Until the accident Marty believes that Paul had "lived to eat" but recently he has noted that Paul is more inclined to "eat to live". Given Paul's clear need for weight reduction, his father is not concerned for the moment about the cause of this profound decrease in his appetite.

[18] Caused by abnormal electrical activity in the brain, grand mal seizures typically involve a loss of consciousness as well as muscle contractions that can be violent.

Despite a significant reduction recently in his daily consumption, food remains an important part of Paul's life and meals provide the structure of his days. Even before the accident when Paul had a voracious appetite, he never took an interest or demonstrated curiosity as to the rituals, customs or culture related to meals. According to Marty, he takes no particular pleasure in holiday feasts or family dinners and does not anticipate birthdays or parties. Autism is a heterogeneous condition and, thus, the ability to participate in the cultural component of food is highly variable.

As Marty talks, it becomes clear that severe food selectivity has marked Paul's dietary intake his entire life. His strongest appetites are oriented towards energy dense foods such as tortilla chips, Chex Mix, cheese and, in particular, chicken nuggets. Placing a package of whole wheat, low fat chicken nuggets on the table, Marty lamented that Paul would eat them at every meal if allowed. His parental strategy for improving Paul's diet is to buy the most nutritionally sound version available (hence the whole wheat breading) and try to limit the consumption of these slightly improved chicken nuggets only to the weekends. Marty hopes that by doing so Paul will be slowly nudged towards enhanced food diversity. Of the two parents, Paul's mother is more inclined to give in to Paul's mute pleadings and provide him with his beloved nuggets (or some other favorite) on a weekday.

Along with a reduced appetite, of late Paul has expanded his diet slightly and is now willing to eat rotisserie chicken, pork and salmon which are rotated into his meal schedule. Pizza, chips, goldfish, and pretzels are also popular, reflecting his strong preference for crunchy textures. His father describes how, in certain moods, Paul will take snacks such as these and break them up in his hands to form a fine powder, which he

will then spread as a dust on the carpet. It is hard to predict, according to Marty, when the food will end up in his mouth and when it will end up on the floor. Marty does not complain but such anecdotes suggest how stressful the feeding of his son must be.

Like many individuals with ASD, Paul is highly suspicious of any foods that are new and unfamiliar. His lunch (typically taken at CSS) usually consists of the familiar: deli roast beef, cod filets or fish sticks, cheese, fruit (often uneaten and sent back home) and a package of *SnackWell* cookies. The school will not use non-preferred foods to try and motivate him to eat other items so his father includes only those items that Paul is willing to eat without inducement into his lunchbox. Asked to describe Paul's diet in a word, Marty offers "limited", "routine", and -- with a sigh -- "reasonable". Like many parents of children with autism, he and his wife pick their battles, hoping to find enough compromise with Paul to avoid mealtime clashes.

Paul's meals are usually offered as finger foods given his fine motor difficulties. While he can use a fork, it is a struggle and requires someone to stand over him and assist. Consequently, he and his wife prefer to let him use his hands and both plan and prepare his food given this restriction. Use of a spoon is rare for Paul. He has never used a knife in the home; when told that he uses an adapted knife regularly in salad class, his father expressed surprise.

Despite his limitations in using silverware at meals, one of his weekly tasks at home is to sort the silverware into appropriate slots in a caddy. His father laughingly explains that Paul, who is undiagnosed but demonstrates profound OCD, will sometimes decide in the middle of a meal that it is time to sort the cutlery! Unable to be redirected, Paul will insist and simply snatch dirty utensils out of their hand for proper sorting.

Paul can drink from a cup but is unable to pour and has never prepared his own snacks. When hungry, he will wander into the kitchen and scrounge for food and eat what he finds unless someone intervenes. Consequently, food must be hidden and/or Paul must be supervised in the home. This is less important now, given his decline in appetite, than it was in the past when his hunger was unending.

Traditionally Paul has been a very fast eater and still tends to gobble his meals down. In response to this, his family placed a television with DVD machine next to the dining table in the home. Now, when Paul eats, he watches a Barney video. The distraction tends to slow his rate of consumption down appreciably and make the family meal more peaceful, though noisy. Marty noted ironically that the only foods that Paul now eats at a very fast rate are non-preferred foods, such as vegetables.

His parents have greater control of Paul for meals served in their home and require that he eat certain foods (broccoli is one of their favorites) before he is allowed access to those items that are highly preferred, such as cheese or chicken nuggets. This arrangement means that Paul is very highly motivated to get through such non-preferred items and will wolf down the broccoli (or whatever) but savor the nuggets. He never gags on or vomits the broccoli but does want to be done with it as soon as possible during the meal, according to his father.

Paul does not drool, except during intermittent seizures. He rarely bites, and his father has never seen him choke or aspirate. He never vomits (unless he is sick) but has been known to spit out food when he considers it undesirable. His only food allergy is to peanuts, but it is a mild one that results in a light rash. Paul has never been on a feeding tube.

As far as his father knows, Paul is not sensitive to food textures though he is very orally defensive. Consequently, brushing his teeth is an ordeal and going to the dentist is traumatic for both Paul and his parents. Marty noted that he has also had a lot of problems with earwax in the past and having that removed was also a high stressful experience for Paul. On one occasion there was such concern about the issue that he was put under anesthetic before his ears were cleaned.

Perhaps due to his limited diet, or perhaps due to polypharmacy, Paul has severe and ongoing constipation. This is coupled with the fact that he is not independent in the bathroom and needs a tremendous amount of assistance, either from aides or his parents. In response to his struggles, his parents feed him a raisin bran muffin, prunes, an occasional apple and water for breakfast. Until recently, his appetite was such that he also wanted cheese at breakfast. His father hopes that the elimination of cheese from the morning meal may help to facilitate his bowels.

Marty indicated that Paul is quite affectionate with both he and his wife but believes that this warmth is highly contextual. He tells the story of visiting Paul at his previous school placement several years before. He says that when Paul saw him in the classroom he did not even acknowledge him. He believes that Paul could simply not place his father outside of the home setting, which Marty views as some form of "cognitive dissonance."

Still, during his hours in the family home Paul will often come find his father or mother and simply take one of their hands. Then, he will guide them to where he wants them to go, typically into the room where he is watching TV. Marty does not quite understand why Paul wants his presence in the room for a few minutes; it is possible that

he is merely lonely. In any case, his father always acquiesces and sits with him for a short period of time before returning to his own activities.

At home, Paul's life is designed to accommodate him and reduce his stress and anxiety. The doors in the house are always locked though he has not eloped in several years. On the last occasion that he bolted, he got several blocks away before they caught up with him. They are unsure if he has outgrown this habit, but the doors remain locked with the understanding that their son has no appreciation of danger and has no life skills for survival.

When he is home and away from the demands of school, Paul's favorite pastime is to watch Barney videos. He will watch his favorites over and over but he needs help from his parents to change DVDs and start the video. Marty is resigned to this highly age-inappropriate activity, saying that he believes that the emphasis on toddler language development is appropriate given Paul's significant developmental delay. Drives in the family car or with his aide in the community center van, and visits to amusement parks are other favorite activities for Paul.

Though in the final stage of his formal education, Paul's treatment plan at this point in his life is primarily pharmacological. He is prescribed a lengthy list of medications (see Table 8-1) and his father also provides over-the-counter drugs. Despite this polypharmacy, his father worries that none of these medications are addressing his significant OCD, which causes significant behavioral problems in the home and school. Marty does feel, however, that the seizures have been adequately medicated as they have become much less frequent of late.

Table 8.1 Paul's Medicinal Intake

MEDICINE TAKEN	PURPOSE
Cetirizine	Antihistamine
Montelukast	Hay fever and asthma
Nasonex nasal spray	For allergic rhinitis
Clomipramine	Tricyclic antidepressant
Escitalopram	For treatment of depression
Risperidone	Antipsychotic His father believes that this is by far the most important medicine that Paul takes.
Propranalol	Used to treat hypertension, anxiety and panic.
Lamotrigine	For seizures and to help prevent self-injurious behavior
Topiramate	For treatment of seizures
Vitamin D3	Overall health
Oyster Shell Calcium	Overall health
Multivitamin	Overall health

Unlike other mental health conditions (358) none of the wide range of medicines used for those on the spectrum address the core symptoms of ASD (359), which are all behavioral. Within the ASD population medication use appears to increase steadily with age such that by the adult years polypharmacy is often the predominant treatment modality (360-362) and has been reported as high as 60% among adults (363).

Like Paul, it is not uncommon for adults with ASD to receive combinations of psychotropic, non-psychotropic, antipsychotic, antidepressant medications, as well as mood stabilizers. There is little research on the effect of these drug combinations, or the

metabolic or physiological consequences. The fact that many in this population are unable to either understand or report side-effects for these medications has not been examined or greatly discussed (363).

As health care professionals come to a greater understanding of the lifetime trajectory of autism, it will be necessary for professionals to have a better awareness of these medications and the possible physiological effects (i.e., weight gain, decreased appetite, metabolic properties, sedation, gastrointestinal upset, and hypersalivation) (364, 365).

Marty believes that the risperidone is the single most important medicine that Paul takes. At present only risperidone and aripiprazole, atypical antipsychotic drugs, are approved by the FDA for treatment of ASD, but only for children and adolescents, ages 5-16 years (366). Risperidone has shown promise in the reduction of irritability, aggression, hyperactivity, anxiety and other behaviors associated with ASD but is associated with a high risk of significant weight gains (214, 365, 367-371) though overall nutritional balance appears to remain stable (214).

Likewise, both risperidone and aripiprazole are associated with "cardiometabolic abnormalities" (372) although discontinuation appears to lead to weight loss and reversal of metabolic issues relatively rapidly. However, almost all of the research on these drugs has focused on children and adolescents on the spectrum so the adverse effects over the lifespan are not well understood.

Paul's father is somewhat leery of the long list of medications that are prescribed to his son. But he is also aware that Paul's level of functioning and quality of life would

plummet if such substances were to be taken away from him. Like so many aspects of his son's life, he has learned to accept it.

8.4.1: Paul's Accident

In early February, 2014 while waiting to board the school bus, Paul fell and dislocated his fibula as well as breaking some of the smaller surrounding bones in his ankle. Marty believes that Paul's weight may have contributed to this fall, though the CSS staff that were present felt it was related to a patch of black ice. Everyone involved – staff, aides, and his parents – were quite taken with the fact that Paul did not cry when the accident happened, though the pain level on his rapidly swelling ankle must have been quite severe. Indeed, Paul only became upset when the CSS staff at the scene of the accident refused to let him stand up on his leg. The aides wanted to keep the weight off of his distended ankle, but Paul was distraught because he wanted to get on the bus and carry on with his day as scheduled.

Marty noted that during the many weeks of the ordeal that followed he never once saw Paul react in any typical way to perceived pain -- i.e. whimper, cry, rub the limb in question, or seek to be consoled. This was not unusual because during his entire life Paul had never responded in a typical manner to scrapes or small accidents. There were no tears or screams of agony in response to any childhood mishaps that Marty could remember. Marty always believed that this indicated that Paul simply had not learned through typical channels, such as social osmosis, cultural traditions and mass media presentations, how to present pain symptoms. But the physical consequences of this most recent accident were likely so significant that his father now contends that Paul simply does not experience pain.

And despite the fact that there was no outright expression of hurt, Paul was very effective in expressing dissatisfaction with the changes that ensued following the accident. Paul hated his cast and an IV he had briefly and tried desperately to get rid of both of them; this only resulted in healthcare professionals placing a highly impenetrable boot over the affected foot. Changes in his schedule and routine were also sources of disgruntlement and agitation for Paul during this period and the consequence was that his behavior became highly unpredictable.

During the earliest days of the accident when the cast was new, his parents tried to heavily sedate Paul in an attempt to get him to stay off his foot, per doctor's order. This effort was unsuccessful and, instead, Paul walked around with his extensive body weight directly on his cast, seemingly with no sense of discomfort. From a physical perspective, Paul seemed unaffected by his broken ankle. It was only in behavioral terms that significant and dramatic changes were noted.

In the post-accident period, challenging behaviors erupted, relationships were interrupted and his education was disrupted. Paul's agitation became a tangible thing. While Paul's emotional state became increasing labile, he also demonstrated increased self-injury. Recent research has demonstrated that a significant relationship likely exists between self-injurious behaviors for those with ASD and reduction of the pain response (347-349). It is estimated that up to 70% of those on the spectrum will display self-injury at some point in their lifespan (342) though lower functioning individuals typically experience it more regularly. Self-injury can be manifested in many ways but often includes head banging, chest and fist pounding, scratching, bruising, and biting. This phenomenon has been studied primarily in children and for those with syndromic autism

(347), and it is hypothesized that self injury can either be a signal of pain or can serve as a counter-irritation to mask pain.

Any progress that Paul had been making as a participant in *Active Engagement* was brought to a standstill following his accident.

8.4.2: Paul and *Active Engagement*

Paul was an early student in the *Active Engagement* program, joining the course in the first formative weeks. He had been a reluctant participant in those initial sessions, always attempting to escape the kitchen classroom and the activities involved. But, over the course of several months, Paul had made profound progress in the course activities to the point where he could produce a salad and was willing, even eager, to consume it. He had defined likes and dislikes in his salad ingredients and was capable of following the flow of the class. Paul was considered an *Active Engagement* success story up to the point of the accident when his boot prevented him from attending.

By late March, Paul had been out of the *Active Engagement* class for over a month due to his accident. Because of the boot he wore over his case, Paul could not walk the distance to the CSS kitchen to participate. Consequently, the researcher approached Paul's teacher to arrange for one-on-one instruction at lunchtime. The researcher's intent was to ensure that the gains made during the Fall classes would not be completely lost during Paul's accident recovery period.

When the researcher arrived at lunchtime to work with him, however, Paul was uncooperative and agitated – highly emotional. By refusing to sit at the worktable, by agitated hand and verbal gestures, and via frantic vocalizations, Paul indicated that he did not want to participate, despite his willingness in the past and his familiarity with the

procedures. Paul could not articulate the problem, but communicated his strong preference through a series of unambiguous behaviors and mannerisms. The most disturbing of these behaviors was the self-injurious thrust of his fist onto his forehead repeatedly, leaving a red welt of dissatisfaction.

It is possible that Paul's upset was due to the context – i.e., working in the classroom rather than the kitchen. Or, it could be that Paul was responding to the change in the way the class was conceived – one-on-one interaction rather than a social grouping. In response to these possibilities, the researcher developed a new plan and arrangements were made with the staff for a small "lunch-bunch" triad in Paul's classroom with the goal of, once again, building class rhythms and reinforcing social relatedness.

Two additional students who were considered to be appropriate in that they might benefit from *Active Engagement* were included in this makeshift class with Paul. Both Yamul and Tayler were male, young adults, on the spectrum who suffered from selective eating patterns. While Tayler was more verbal, Yamul was more socially engaged and curious about the class activities.

After this secondary group was established, several classes were held for assessing baseline. During these initial sessions, Paul spent most of the time dozing, asleep on his folded arms at his desk. When awake, he would observe the class activities warily from a distance as Yamul and Tayler learned the class rituals, processes and activities.

After several classes the group finally began to develop a natural tempo. It was, however, almost three weeks before Paul was really back in the mix of the class. Paul finally made a salad again – the first in almost two months -- but only ate a half-dozen

bites, whereas before he would have wolfed down the contents of the salad he had prepared.

This modest progress was encouraging, but at the very next class Paul indicated that, once again, he did not want to participate at all. He sat across the room, watching the researcher working with Yamul at a table where they were singing, cutting, and interacting. After some period of observing these activities across the room, Paul quietly came over and joined the researcher and Yamul at the table. He did not participate, but he also did not interfere or display any challenging behaviors. Instead, with a quiet body and manner he simply watched from up-close what was happening and followed the direction of the activities. This behavior, though not overtly promising, needs to be understood in the context of Paul's behavior since the accident when he had almost violently rejected all overtures of inclusion in *Active Engagement*.

The following week Paul's cast was removed and he rejoined the original class, which had been meeting regularly over the intervening weeks since his departure. At first, he was distraught to be back in the class and there were often real tears in his eyes, a continuation of the highly emotional behavior that had been apparent since the accident. After several weeks back in this regular setting with the established routine, Paul was able to once again participate in small ways, though initially he did not choose to consume – traditionally his favorite part of the class.

There were numerous telling moments during the next few weeks that provided some insight into Paul's changed state and demonstrated how volatile his behavior had become. For example, during one of the early weeks he walked into the classroom to begin a class and the researcher asked him if he would like to make a salad on that day.

Paul responded with a nod of his head, an immensely communicative gesture for him. On another day, he carefully watched the other participants but become distraught and pounded his head if compelled to do anything more than merely observe. The pronounced red welt of self-injury on his forehead spoke loudly to his dissatisfaction.

The steps back into the class were tentative, not progressive. Movement was almost random and took a different path than the one he had taken prior to the accident in the early, initial sessions of *Active Engagement*. There would be flashes of the old Paul at moments, and then a glimpse of the new, more emotional Paul. His mood changed hourly and with no apparent mechanism of change.

An important breakthrough came with an activity that the researcher named "The Dipping Game." In this activity, small cups of various types of colorful salad dressing were put in front of Paul. The researcher began by pointing out the differing colors of the dressings and questioned out loud what they might taste like. She modeled the activity for Paul by cutting a slice of cucumber and dipping in one of the colorful dressings and tasting it. She then asked Paul to cut one of the vegetables that he had on his cutting mat. When he had finished slicing a cucumber, the researcher again modeled the activity by dipping it into one of the cups in front of Paul. After repeated modeling, Paul readily copied the researcher and appeared to demonstrate curiosity about the colorful liquids in front of him. After some time he was freely cutting and dipping the vegetables into the various dressings, even making a point of deliberately trying different cups.

After doing this activity for some time, Paul unexpectedly reached across to the women (Katie) sitting next to him who was preparing an individualized salad. He was stopped only by the researcher who told him that he could have a bowl of Katie's salad,

but that after this one time he would have to make his own. He acknowledged acceptance and, in the end, consumed three bowls. It was the most he had participated and/or consumed since the accident. And yet, it looked nothing like his participation patterns prior to the accident.

Following this moment, Paul's participation in the class was varied. Some days he would sleep through the class; other days he would arrive but be agitated and desperate to leave. Then there were moments when he stayed, participated, and consumed his own salad. It became hard to predict which Paul – the old or the new -- would show up for class.

The researcher noted over the course of the weeks that following that Paul's progress from the first half of the class – before the accident – was quite different than the path that he followed in the second half. It was not simply a matter of retracing the steps he had taken initially and following them to the same achievements. Whatever the cause, the accident (or the events surrounding the accident) changed the dynamic for Paul and new and different tools were required to reach him.

Paul's parents, as well as many of the CSS teachers and staff, were relieved at Paul's apparent insensitivity to pain. No one wanted him to suffer excessively. While his is a natural – and humane – response in the face of an accident for someone with so few coping skills, in the final analysis it is clear that Paul *did* suffer and that the accident was cataclysmic for him.

8.5: Discussion: Strengths and Limitations

Whether or not Paul truly felt pain from his broken ankle is unknown. But his behavior in general, and in subsequent *Active Engagement* sessions in particular make clear that the accident was profoundly significant for Paul. The history provided by his father uncovered a high level of suffering over such mundane health care rituals as dental visits and ear cleanings. It can only be surmised how ill prepared Paul must have been for broken bones, an emergency room, and the sensory discomfort of casts and IVs.

Individuals on the spectrum, especially those as severe as Paul, cannot simply modulate themselves given the sensory abnormalities that they experience. Likewise, healthcare professionals are unprepared to deal with individuals who do not have the capacity to fully participate in their own healthcare. A recent survey of medical doctors (373) found that only 36% of all respondents reported receiving at least minimal training about treatment for adults with ASD. Over 50% indicated that more training was warranted to work with this population.

Among the participants of *Active Engagement*, Paul's story was unique in that his journey was one of disruption and inconsistency. In that sense, his account is situated as unusual, making generalizability questionable. Though Paul's experience was idiosyncratic, his response to pain and trauma was not. Paul never cried when he broke his ankle, though the pain was likely some of the most severe that he will ever encounter in his life. But Paul wept profusely when brought to salad class and asked to participate, an experience that he had enjoyed before the accident.

Paul's expression of pain was abnormal, not what was expected, and likely represented vast pathologies in sensory processing, manifested over many domains. The

pain, discomfort and stress caused by the accident were subsequently expressed in the behaviors that he demonstrated during his recovery period including self-injury, weight loss, daytime sleep, agitation, labile mood changes, and alterations in appetite. Reverberations from this trauma clearly manifested themselves in many ways that disrupted the educational and social process and compromised Paul's ability to learn and participate in the weeks and months that followed.

In this particular case study there was a broken ankle– an inciting incident -- that could be used as a marker. Comparing behavior before and after the accident provided the means for building a causal relationship. While there has been some research and case studies on the pain response for those with ASD, these have typically focused on those with high functioning autism. For example, content analysis of self-accounts and published autobiographies of individuals with high functioning autism (343) noted a wide range of both hyposensitive and hypersensitive behaviors.

For many individuals on the spectrum, however, the ability to communicate directly regarding an inciting incident – be it trauma or illness -- may not be possible. What if Paul had suffered, not from a broken ankle, but from a hidden health concern such as diabetes, or pharmacological side effects? Unless stakeholders understand the relationship between pain expression and challenging behaviors for this population there is no reason to search for an underlying cause of behavior change.

It is expected that, as rates of obesity rise among adults with ASD, levels of chronic disease will accompany it. The symptoms and outcomes related to these conditions may go unreported (and hence undiagnosed) due to the fact that they may be

expressed in alternative ways that can be dismissed as inherent to autism. As Paul's story illustrates, underlying physiological causes need to be one of the first lines of inquiry.

If the narrative analysis provided herein does not satisfy the biomedical-positivist approaches that have predominated in the research related to health care, it contributes greatly better understanding how those with communication deficits express themselves as to discomfort and pain. This population does not have the ability to completely participate in their own healthcare and new means, such as that discussed here, are going to be necessary to service this very at-risk population.

The issues raised in Paul's story have implications for applicability across the entire spectrum. A more specific and significant shortcoming of this study was the researcher's difficulty in setting aside feelings of tremendous empathy for Paul's suffering in order to objectively address his behavior. It was not easy to watch Paul become self-injurious and her emotional response to the topic is apparent in this narrative.

8.5.1 An Alternative Interpretation

> The gradual building of an explanation is similar to the process of refining a set of ideas, in which an important aspect is again to entertain other *plausible* or *rival explanations*. As before, the objective is to show how these rival explanations can be supported, given the actual set of case study findings" (295).

A fundamental part of undertaking qualitative analysis is to acknowledge the existence of different ways to arrange and, hence, interpret data. An alternative interpretation of Paul's behavior is to see the events of his recovery as a simple

regression. Paul became stressed due to changes in his routine brought on by a broken ankle. Consequently, he retreated into his interior world where research could not follow.

Such a perspective puts the emphasis on autism as a vast, unknowable mystery. It allows those responsible for the health care of this population to simply dismiss the unexplained as an incomprehensible phenotype. It is time to look for the causes of behavior in underlying sensory dysfunction, to accept that such behaviors have a purpose, even if harmful.

Paul's is nonverbal, but his behavior gave expression to the tremendous trauma he experienced during and after his accident. He told everyone who would listen about his trauma through the only means of communication available to him. By arranging the data and interpreting his actions through the lens of his accident, it was possible to see the subsequent events as the consequence of his broken ankle.

Paul's story was unique among the participants of *Active Engagement.* Despite this, his narrative still holds generalizability given that the understanding of the pain response on the spectrum is only beginning to emerge. Viewing Paul's behavior through this prism strengthens the external validity as well as reliability of this case study.

It is time for all stakeholders to start observing behavior on the spectrum as a form of communication, rather than just as another idiosyncrasy of the condition. Doing so in this case study gave voice to one nonverbal individual and allowed him to shed light on what happened to him.

Chapter 9: Unique sensory abnormalities feed unique eating disorders:

Parents Talk about their Adult Autistic Children and Food

> "Autistic children often present with bizarre eating habits, feeding difficulties and restrictive diets" (213).

9.1: Introduction -- The parenting experience of eating disorders on the spectrum

Of late there has been much interest in research addressing how the parents of children with autism cope with the unique pressures that they face (374-381). Widespread in this literature is the understanding that individuals with autism display unique and highly challenging behaviors when compared with other disabilities and that, because of this, caregivers for children with autism typically have greater stress and anxiety than those dealing with other developmental disabilities (382, 383). A variety of factors have been demonstrated to increase stress among parents with children on the spectrum. Severity of the disability (384, 385), minimal ability to express emotion (386, 387), or externalized behaviors outside of the core symptoms, such as hyperactivity, self-injury and eating disorders, have all been shown to contribute to parental anxiety and pressure (388-391).

The parents of individuals who participated in *Active Engagement* were not exempt from these stressors and, through in-depth interviews regarding their child's developmental history, make clear that food played a pivotal role in the sensory abnormalities their child experienced. Although parental pressure was not directly addressed, the resulting interviews demonstrate the ways that feeding pathologies and eating disorders contributed to family dynamics. Indeed, for some of the parents interviewed, the family dinner table was a primary source of familial discord.

Some of the *Active Engagement* participants discussed herein have profound eating disturbances, and all of them have struggled with building a healthy relationship with food. Despite the severity of the issues raised in these interviews, none of the parents interviewed had professional help to guide them or address these mealtime or food-related behaviors, a trend seen across this entire population (154).

In part, this is likely due to the limited number of specialists dealing with eating and feeding disorders for this population. Professionals who typically work with feeding issues on the spectrum are often psychologists, occupational therapists (OT) or speech and language pathologists (SLP) rather than nutritionists. While SLP's address dysphagia and OT's are focused on the mechanics of the bite, neither SLPs nor OTs are likely to emphasize the nutritional component. Psychologists, on the other hand, typically invoke behavioral interventions to address the eating disruptions that are so widespread in autism, but are less interested in the family environment of mealtimes.

As the interviews that follow make clear, parents responded to their children's feeding behavior in many different ways. Some parents devised strategies and rules; others made ongoing bargains with their children. Some parents simply gave up, worn down by the unending battles. Captured in these stories is the recognition that the act of eating was not simply an incidental behavior for those on the spectrum, but rather another theater in which aspects of their condition played out.

9.2: Eating disorders and their consequences

As addressed in Chapter 2, it is estimated that 90% of children on the spectrum

have some sort of feeding or eating pathology (46, 48, 194).[19] Yet, despite the widespread nature of this problem, it is not considered as a diagnostic criteria for ASD (167). For some individuals, these pathologies are idiopathic, though underlying medical or physical complications as well as sensory abnormalities contribute to their manifestation (167, 392). Perseveration, neophobia, social compliance deficits, and biological food intolerance also likely play a role (393). External factors that affect these conditions may include parental anxiety, passive reinforcement of undesired feeding patterns, and overall communication deficits that make food negotiation difficult. In the end it is most effective to see these eating problems, particularly self-limiting food specificity, as the logical extension of very narrow interests and activities that define this population (199).

Reported eating disorders are varied but self-selectivity of food and limited variety predominate (45, 167) though rumination and pica are also demonstrated (167). Aversive eating behaviors (i.e., refusal of foods, choking or gagging, as well as expulsion of food with no physiological cause) are typically differentiated from sensory-based feeding problems (i.e., aversions to specific food color or texture).

Numerous researchers have explored the relationship between self-limiting diets and nutritional status. From a medical and nutritional perspective, poor eating habits can cause or contribute to a range of problems including malnutrition, growth delays, placement of a feeding tube, and deficits in psychological, social, or academic skills (196). Though, in general, health does not appear to be compromised for children on the

[19] By convention, disordered eating in childhood is considered a feeding disorder but the same issues for adults are referred to as an eating disorder.

spectrum with food selectivity (43, 196), it should be noted that nutritional status is traditionally assessed primarily via BMI. Several studies have found that assessments utilizing anthropometric measurements (as well as, or in lieu of, BMI) typically document greater body fat in those with ID or DD than do measurements utilizing BMI exclusively (27, 394). The issue of whether BMI is an accurate assessment tool for those with disabilities requires greater scrutiny.

The nutritional assessment of children on the spectrum with food selectivity has demonstrated no evidence of a failure to thrive or a reduction in growth velocity (which is a key indicator of nutritional health). Nevertheless, growth status can mask larger problems related to underlying nutritional deficiencies (196). There is no evidence that parents of children on the spectrum are deficient in nutritional knowledge or awareness of child's activity level, important components of nutritional status (157).

The testimonials included in this chapter demonstrate that eating patterns can cause stress for parents, siblings, and even for the individual with autism; eating is, after all, a very emotional act. Feeding one's child is one of the most nurturing roles a parent will perform. But, when faced with a myriad of pathologies related to consumption, parents of children on the spectrum can find themselves dreading meals. A small study of eating patterns among parents with autistic children (213) found that every single participant reported that they had attempted to introduce new food to their child. When this effort failed, they typically ceased their efforts in an effort to maintain peace at the dinner table.

9.3: Design and Methodology

As part of the *Active Engagement* consent process, parents were asked to participate in an interview with the researcher to discuss their child's eating and developmental history. In anticipation of this interview process, in-depth interview guidelines was developed (See Appendix A) that outlined the general information to be collected. Questions were designed to develop topics related to patterns of food consumption and behavior associated with their child's behavior outside of the context of the classroom. Other questions in the interview addressed official diagnosis, comorbidities, medications that might affect appetite, and eating patterns and pathologies. Demographic information was also collected as part of the interview process and included questions related to age, childhood, siblings, weight and height, as well as family patterns with food and meals.

Interview questions were largely open-ended and parents were allowed to lead the conversation to topics that they believed to be important in their child's progression into adulthood. While feeding problems were the central focus on the interview, many different issues arose in the discussion process.

Most parents were interviewed in person, either at their homes or in the CSS facility in Gaithersburg, MD. Two parents chose to be interviewed by phone, though this was not as productive and conversations with the researcher tended to be shorter with less detail. Parents who were interviewed by phone also asked fewer questions and were less curious about the researcher's study and their child's participation in it. Despite these limitations, phone interviews were allowed by the researcher to accommodate parental schedules, which were often quite hectic. Each parents told a different story but, in their

totality, they demonstrate that food problems saturated their child's developmental history.

The interview outline and demographic questions (See Appendix A) were adapted from Williams and Foxx's publication, *Treating Eating Problems of Children with Autism Spectrum Disorders and Developmental Disabilities* (202).

9.4: Data Analysis

The collected interviews that formed the basis of this chapter produced a tremendous amount of raw data. In Chapter 8 data analysis was undertaken through a technique of 'playing" with the information, but this was not an appropriate strategy for this chapter given the scale of information collected. In this chapter case study analysis was, instead, based on the building of descriptive categories that served as a mechanism to sort the data in a search for leitmotifs. This type of thematic analysis has long been used in qualitative analysis as a categorizing strategy for making sense of multiple strands of information. Indeed, it is one of the most effective mechanisms in qualitative studies for moving beyond broad levels of raw information towards the development or discovery of meaningful themes and/or patterns.

9.4.1: Analytic Frame

In this chapter the framework of the thematic analysis was provided by the interview form itself (see Appendix A). The general questions to be asked ensured that the ground covered in each interview was comparable. Parents were allowed during the interview process to elaborate at any point in the process and the researcher followed them into various subject areas. Some parents wanted to talk extensively about how far

their children had come; how difficult the childhood years had been in regard to eating patterns. Others emphasized the difficulties of the now, indifferent to childhood patterns and only concerned with the events of current meals. Ensuring that all of the questions on the interview format were covered meant that analysis of comparative data was possible, but also resulted in several lengthy discussions when parents wandered into new territory.

9.5: Parents talk about their child and their feeding history

9.5.1: Andrew

Andrew is a 23-year old male with ASD. Since his parent's divorce at a very young age, Andrew has been regularly transported between dual homes with competing philosophies about food. He is sweetly compliant during the sessions of *Active Engagement* and though minimally verbal, seems very interested and engaged in the class events. Andrew always produces a beautiful salad during the 60-minute class, and enthusiastically consumes it.

According to his mother, the food environment at his father's house involves lots of processed and fast foods, which Andrew will readily eat it, if offered. She believes that her own home (where she lives with her second husband) offers more nutritionally balanced meals and whole foods. As she talks, it is clear that she gives significant thought to meal planning and the types of foods that she has available for all of her children, though they are all now young adults.

His mother tells the researcher that, even at a young age, Andrew had his own idiosyncratic patterns of eating that went beyond fussy and required a great deal of time

and energy to address. For example, for long periods of time Andrew had refused to eat foods that were either cold or sweet. Likewise, Andrew demanded specific meat and vegetable combinations at meals and would not allow their rearrangement or any type of substitution. Andrew lacks the ability to explain or elaborate as to his food preferences so the reasons behind any of these food rules remain unknown. The consequence for his mother is that every meal had to be carefully thought through and that she often felt her options were excessively narrow at mealtimes.

Like his mother, Andrew enjoys a healthy BMI (22.8). This is despite the fact that all of Andrew's siblings are heavy and share the same dual home arrangement. When asked how Andrew indicates that he is hungry, his mother said that he never asks for food but will simply "sneak" into the kitchen to grab a quick bite. As his weight is not currently a problem, this behavior is allowed, though not encouraged. Andrew is completely independent at meals and can use a spoon, fork and knife as well as pour his own drink and prepare simple snacks, if given a few prompts. Most of his self-prepared snacks involve opening a can and microwaving the ingredients but he needs no supervision to accomplish this. There are no current oral-motor problems except for teeth grinding, for which he wears a mouth guard during sleep.

Asked to describe her son's diet, his mother offered "healthy." She follows this by explaining that – at her home – there are no more than 2 servings allowed, there is no junk food and all of the available snacks include fiber. She did concede that Andrew drinks an excessive amount of diet soda, and she is currently working on getting him to cut back on this. The atmosphere at the house of Andrew's father is more of a mystery to her, but she is aware that there is much more junk food.

9.5.2: Lindsay:

Lindsay is a 23-year old female with ASD. Lindsay has been in residence at CSS for almost three years, and was given residential placement due to issues of elopement that developed around the age of 20. During the progression of *Active Engagement* Lindsay has developed into an enthusiastic participant though she is strong-willed with very set ideas about how the class should proceed. Lindsay has progressed so that now she will always seriously consider trying new ingredients (rather than ruling them out immediately) and will actually taste them about half the time.

Her mother indicated that Lindsay was not a picky eater as a child and always liked most foods during the early years. She felt her daughter had a healthy appetite as a child and reasonable eating patterns. Moreover, during the early years she saw no evidence of sensory issues, particularly in the realm of food. Consequently, Lindsay remained quite thin until adolescence when her weight exploded.

Around the age of 15-16, Lindsay was put on risperidol, an anti-psychotic medication with a known side-effect of significant weight gain. Her mother noted that, from that point onward, Lindsay experienced an immense increase in both appetite and food intake. The subsequent "enormous" weight gain meant that the behavioral problems were harder to control as Lindsay was so large.

Her mother remembers this period well and reports that Lindsay's drive to eat at this time was almost unending. For whatever reason she did not seem to experience satiety (or didn't understand what it meant) and she would eat so much at one sitting that she would literally throw up. Her slender frame quickly packed on the pounds and – for the first time – Lindsay became "obsessed" with food.

Currently Lindsay's BMI stands at 27.1, marking her as overweight but not obese. Since moving into a CSS residential facility Lindsay has experienced a 50-pound weight loss. Her mother believes that this is due to the fact that her rate of eating has slowed down considerably, which her mother argues is partially due to newly prescribed reflux medications. With meals moving along more slowly now, her mother feels that Lindsay now has an opportunity to "feel" full and thus can better self-regulate her food intake. Lindsay has slowed down so much during meals that during *Active Engagement* sessions her aide will have to occasionally prompt her to eat faster so as to maintain the daily schedule and not be late for the next activity.

In her childhood Lindsay participated fully in family meals; she can use all utensils appropriately and can remain seated throughout a meal. This gave way over the years and evolved into separate meals for Lindsay for a variety of behavioral reasons. Nowadays when Lindsay joins her family for a meal her behavior is very unpredictable and, consequently, it is no longer possible to eat out at restaurants.

Lindsay experiences constant polydipsia, a possible consequence/side effect of her polypharmacy, and drinks tremendous amounts of water throughout the day. During a certain period when she was taking lithium she began to drool but that ceased when she was taken off this medication. Lindsay bites her knuckles but has no other oral-motor issues.

At her residence, Lindsay feeds her self and can make a simple snack but must have permission from the residential staff. When Lindsay is hungry she will express herself verbally in simple language and there are far fewer food battles now than there were in the early days.

When asked to describe her daughter's diet, her mother, focusing on the changes that CSS residency has brought, lamented Lindsay's current dietary options. Still, she is relieved to see Lindsay's weight settle at something more healthy.

9.5.3: Melissa

Melissa is a 25-year old female with Developmental Disability and schizophrenia; she did not receive a diagnosis of autism due to the fact that her schizophrenia was late onset. She lives at home with her parents and several siblings. Over the course of her time in *Active Engagement* she has grown into an independent participant who can be given tasks of responsibility. Moreover, she is increasingly verbal and social. She takes pride in her salads and is very easy to work with.

Melissa's mother reported that she had no real feeding problems as a child though clinical tests during childhood indicated borderline cholesterol issues for which no medicine was prescribed. Typically when Melissa was little she would eat almost anything put in front of her. Even today she is able to calmly eat dinner with the entire family with no behavioral problems.

When asked what foods that Melissa dislikes, her mother could not name a single food. She did concede that Melissa eats "a little on the fast side" though she does not feel that Melissa rushes through any meals excessively. Melissa has no oral motor issues or feeding problems. She is completely independent with food and can prepare her own breakfast and lunch.

Melissa's BMI of 27.3 positions her as overweight, but not obese. When asked how to describe her diet, her mother responded "well balanced."

9.5.4: Francis

Francis, a 23-year old male, is diagnosed with ASD. He lives at home with his parents and one older brother. Francis's trajectory in *Active Engagement* has been dynamic. In the early days he made a point of escaping from the class as soon as possible, with very little participation and no enthusiasm. Currently, he has found a role in the class that he is proud of and has developed excellent salad construction skills. He is finally willing to eat something he has named a "salad" though it only contains a handful of ingredients. Getting him to this even modest achievement took substantial effort.

Francis's mother notes with weariness that he was a highly selective eater from very early in his childhood with very little variety and numerous self-created rules. That pattern continues to this day; she went on at length about what he was and was not willing to eat. There is very little room to compromise though he occasionally surprises her. If anything, she admits, his diet has become more restrictive since he has transitioned into young adulthood.

Currently his dinners are within a very narrow range that includes Chef Boyardee, chicken strips, macaroni and cheese, and pizza. Recently, he added hot dogs to his rotation when his mother simply presented it at dinner one night with no commentary and – to her delight – he accepted it without a fuss. This was a highly unusual occurrence; his general attitude to new foods is one of deep suspicion. He recently surprised his mother again by deciding, out of the blue, that he would no longer eat ice cream from a bowl and now insists on having it in the form of an ice cream bar. He cannot, or will not, explain the reasons for this decree but she typically complies.

Francis also has had a long history of having difficulty swallowing liquids and, consequently, tends to avoid them – particularly water. In his childhood Francis drank only milk, though by 8 years of age he had finally progressed to juice and soda. Nowadays his mother is determined to get him to drink water during the day but has only had modest success. Though he talks about drinking water often, he is rarely willing to even take a taste.

Food textures were always an issue for Francis and his self-limiting diet is clearly based on oral and tactile defensiveness. The textures he was willing to permit into his diet do seem, however, to rotate and are not static. Francis also demands certain color combinations on his plate before he will consider a meal acceptable.

According to his mother, carrots are currently the only vegetables that he will eat. If the family eats out at a restaurant, it must have a very familiar menu or he will panic and refuse to eat. The good news of late is that Francis can now microwave items himself and thus can prepare a simple dinner for himself without clashes at the table. This is also useful given that Francis is a very quick eater and is typically done eating long before his family.

With a BMI of 30.8, Francis is now obese. A recent medical visit found that Francis was also suffering from low vitamin D which is being addressed through supplements. As a child Francis was never placed on any special diets and has no food allergies. There are no particular oral motor issues in play at present.

If Francis is hungry, he will simply proceed to the kitchen and prepare himself an acceptable snack based on his elaborate set of rules. When asked to describe his diet, his mother responded with a very honest "poor." She has pretty much given up any hope of

changing his diet, but has found far more success in keeping him physically active. He jogs with her, and participates in numerous activity programs for the disabled.

9.5.5: Rick

Rick is a 24-year old male with ASD. He has lived in a CSS residence facility for several years since an incident when he pushed his father. Due to his violent explosions, he was given a residential placement and his behavior has been more stable since this transition. Rick was initially a very reluctant participant in *Active Engagement* and wanted to be out of the room as soon as was possible. He has progressed over the course of the year and now enjoys himself, stays the entire hour, though he only partakes of a few ingredients.

Rick's mother explained that as a child Rick had far fewer eating difficulties than he experiences today as a young adult. In his childhood years the biggest feeding concern was that Rick would eat to excess and stop only when he had vomited. She believes that Rick did not really understand what fullness meant and, thus, did not have the mechanism to stop. During these binges Rick would often gag violently, which she recalls as terrifying.

When Rick was a child his mother had him on the gluten-free/casein-free diet but does not believe that it was particularly effective. She admits, however, that she was not particularly rigorous in the application and has subsequently noted numerous children who have done well on this diet. This is the only dietary intervention that Rick has participated in.

In his current residential environment, Rick helps make dinner and eats with his roommate at the dinner table. He is a quick eater and staff are continually coaching him

to slow down his rate of eating. Residence staff have also worked successfully to eliminate his binge/vomit cycles.

Rick suffers from chronic constipation and sleep disorders, both common among adults with autism. Rick has no food allergies but the thorazine that he is prescribed causes excessive drooling and, consequently, the front of his shirt is often drenched. Likewise, another prescribed medicine, seraquil, causes him to have an insatiable thirst and he will often interrupt his salad production to drink a large glass of cold water. In the course of an hour class it is not unknown for Rick to drink 48 ounces of water.

Due to other medications with side effects that leave him unable to properly regulate his body temperature, Rick sweats heavily and extreme heat can be hazardous for him. The thorazine also causes him to have a slight hand tremor, which is noticeable but does not interfere with most activities. He is able to use a spoon, fork and adapted knife with reasonable proficiency; he is not allowed to use cutlery in his residential placement. He can drink from a cup and pour unless his tremor is particularly bad and can prepare a simple snack for himself.

With a BMI of 32.1, Rick is obese. His diet is particularly heavy in prepared and processed foods. He has a – seemingly – never-ending desire for pizza and comparable foods. Rick is verbal, so if he becomes hungry he will ask for what he would like; he does not simply take food without permission.

When asked to describe Rick's diet, his mother responds with "varied." She thinks he has made some progress since moving to the new residence so is optimistic about his long-term eating patterns.

9.5.6: Caroline:

Caroline is a 22-year old female with Down's Syndrome. She lives at home with her two sisters and parents. She is a sweet and bright participant in *Active Engagement* and has a quiet way of expressing her own personality. She is proud of the fact that her chunk salads are distinctive and enjoys the fact that the researcher continually points this out to the other participants.

Caroline's mother explains that since birth Caroline has been a very slow eater and this factor has played a profound role in all family meals. Her mother describes how, during the early years, Caroline was taken care of during the work day by her grandmother who "spoiled" her so that she ate only a dozen items for the first few years of her life. Her mother decided at one point that this was not acceptable and took control of her daughter's diet. At that time Caroline was exclusively eating sandwiches, and her mother started by putting new food items between two pieces of bread and declaring them to be "sandwiches". This novel approach was successful and Caroline slowly developed the ability to eat anything in this manner. Tricks such as this are no longer necessary according to her mother.

Nowadays, the problem is primarily the extended period of time that it takes Caroline to complete her meal. She has certain rituals related to meals (i.e., she likes to wear pajamas at dinner) but none that are excessively onerous for her mother. Caroline independently uses a knife, fork and spoon at the table. She comes home from CSS on a bus and lets herself in to make a snack independently.

At present Caroline is refusing to eat any foods made with sugar, primarily because her best-friend Sasha is watching her weight by giving up sugar. Caroline's food preferences are now quite standard options, and she eats the same foods as her peers.

At a BMI of 28.3, Caroline is overweight, common among the Down's Syndrome community. There is very little snacking for Caroline, primarily due to her own internal barometer which seems to demand only 3 meals a day and a small snack after school. Other than her weight, her health is quite good though she is routinely low in Vitamin D. Caroline is very sensitive to temperature and has come close to fainting in extreme heat; the cause of this is unknown but it is not a medical side-effect as she is not currently taking any medications.

Caroline has no oral motor issues though certain meats, such as steak, have to be cut into very small pieces or she will choke. She is not particularly sensitive to food textures but there is some relatively minor teeth grinding.

When asked to describe her daughter's diet, her mother offered "pretty healthy". She has little to complain about given that mealtimes (when the family eats together) are very peaceful. She is somewhat amused by the new decree for no sugar and wonders how long it will last.

9.5.7: Sasha

Caroline's best friend is Sasha, a 23-year old female also with Down's Syndrome. Sasha lives at home with her extended family of Philippine descent. Sasha is a stellar participant in *Active Engagement* and routinely makes salads that are noted by the other participants for their attractiveness and skill. As the program has progressed Sasha has become more confident – and even bold – in her choices.

According to Sasha's mother, in her infancy Sasha had numerous feeding issues, particularly related to the suck reflex. As she got older her mother reports that new feeding problems developed. In particular Sasha would often have eating binges of favorite foods; rice is one food item that she continues to crave and will eat in excess if given the opportunity.

Nowadays Sasha is "boy-crazy" and thus is conscious of her body, says her mother. Consequently Sasha is currently very careful about what she eats so as to control her weight. With a BMI of 23.5, Sasha's weight is in the normal range. To control this, she has given up sweets; this choice/restriction has spilled over onto Caroline's eating behavior as they are constantly together.

Sasha eats dinner with her family as a unit. Her mother notes no problem behaviors during mealtimes though Sasha is always the slowest eater. Rice continues to be one of Sasha's favorite foods. To reduce her consumption of white rice, her mother recently started to include brown rice in their meals in hopes of introducing more fiber. This is particularly striking given that there is no cultural tradition of brown rice in the Philippino diet. To date, her mother has had mixed results with this small replacement.

Sasha is not independent in the kitchen; she will ask for something if she is hungry and passively wait to be served. Her mother's goal is for Sasha to prepare a simple snack for herself but they have a long way to go to accomplish this. Despite the fact that Sasha is very capable during the *Active Engagement* sessions and has developed excellent cutting and chopping skills, she has not utilized these skills sets in her own home. Instead, she tends to wait to be served at home rather than take the lead.

Sasha has no food allergies and no oral motor issues except occasional choking. She avoids all slimy textures, and is particularly averse to okra. She grinds her teeth during sleep.

When asked to describe her daughter's diet, her mother suggested "healthy". Sasha is unusual for someone with DD in that she is conscious of her body, and understands the relationship between what she eats and how much she weighs. This is likely due to her age and her emerging interest in boys and demonstrates how socially competent she is compared to the participants in *Active Engagement* who are more typically on the spectrum.

9.5.8: Grant

Grant is a 21-year old male with ASD. He has lived at a CSS residential facility since he was 12 years old due to severe and challenging behaviors including self-injury and pica. Grant has participated in *Active Engagement* via one-on-one sessions as his severe pica made him disruptive in social settings; in the early sessions he would simply eat anything her could grab, including bottle caps, banana peels and napkins. The researcher found that most of his disruptive behaviors could be dealt with through active choice; given options, Grant always responded appropriately. With more options available to him, he made tremendous progress during his time in the program.

His mother explained that, though Grant was a relatively good eater as a baby, from the age of about 5 he developed intense sensory preferences for foods. At one point, she explains with weariness, he was only willing to foods that were orange and yellow. Thankfully, color restrictions on foods have given way to a much broader

tolerance. He is very open now to many different kinds of food though he typically wants too much of it.

Grant has lived many years now away from his family; his parents were divorced soon after he was placed in residential housing and now he rotates between them for family visits. His parents try to include Grant in special occasions and family meals but it is hard to do since each is remarried. Although there is an occasional Shabbat dinner, Grant struggles to stay seated at the table and much energy is invested in keeping him in his seat. Recent challenging behaviors in public as well as severe pica have meant that they can no longer take him out to a restaurant; there have been too many incidents in public of late. Instead, they typically bring in a pizza (one of Grant's favorites) and consume it in one of their homes.

When Grant is distraught, he will try to eat anything available and many nonfood items have found their way into his stomach. His mother tells the story of two years prior when he had swallowed a rubber glove that could not be passed and had to be surgically extracted. Food has to been hidden in his residence because he will eat anything he finds without seeking permission.

His mother is also concerned about his OCD which she feels has gotten worse of late and which makes shared mealtimes even more chaotic. This will play itself out in Grant's insistent on pulling off all labels, or pealing away all paper from bottle tops. During shared meals his mother says that Grant needs a lot of prompting to carry through and stay in his seat, but that the time it takes to complete a meal is "about right". He can use utensils appropriately and can pour his own drink and prepare a simple snack.

Cutlery is not typically given to him in the residence, but he used an adaptive knife in *Active Engagement* with some skill.

Left to his own devices Grant has a strong preference for simple carbohydrates and processed foods. He is particularly fond of pizza, macaroni-and-cheese and French fries but strongly rejects all layered foods, such as sandwiches even though he may like all of the individual parts. Grant will occasionally put too much food in his mouth and the consequence is that he will gag; this typically occurs with foods that are highly preferred as if he was excited and did not have the impulse control to slow himself down. His mother said that the best way to handle these incidents is to coach him through the process of chewing and swallowing. In the past, he has binged so excessively that he has vomited, though this does not happen as much of late.

Grant has self-injurious behaviors that are the cause of many bumps, bruises and cuts, but they do not typically interfere with eating. He also grinds his teeth but has no other oral-motor difficulties. Whether due to biological causes, his diet or polypharmacy, Grant has numerous gastrointestinal issues. Like many of his peers, he suffers from chronic constipation. With a BMI of 24.7 he is at the high end of normal. This concerns his mother as Grant had been quite slender his entire life. She is unsure if the pounds that he has gained in the last few years are due to diet or his high level of polypharmacy but she lives in dread that he will become obese. It is, she said, much easier to keep them from getting heavy than it is to get them to lose weight.

When asked to describe Grant's diet, his mother suggested "highly controlled". Grant does not enjoy, like his peers, any freedom in food choice whatsoever. Every

move that he makes and every thing that he places in his mouth are carefully watched. They have to be: Grant can very easily harm himself.

9.5.9: Lee

Lee is a 22-year old male with ASD. He lives at home with three siblings and his parents. Lee has become quite adept at producing salads during his time in *Active Engagement*. He has been held back from eating these salads by the fact that lunch-time is immediately post class and his lunch box is always filled with the highly processed foods that he prefers. On numerous occasions the researcher has noted entire packages of sugar wafers and large containers of cocoa puffs emerging as part of his lunch fare. Despite his gains in self-autonomy and self-efficacy, Lee is burdened with a preference for junk foods that keeps him from enjoying more nutritionally sound options.

Lee has always demonstrated a high level of food selectivity. When he was younger his mother said he would only eat certain foods from a very short list of what he considered acceptable choices. With the passage of time, however, she believes that he has developed into a less selective eater and that the number of foods that he is willing to consume has grown, though it is not lengthy. Lee eats all meals with his family and his mother reported that such mealtimes are very calm, with few behavioral eruptions.

She acknowledged that Lee craves carbohydrates of all kinds and that he "cannot get enough of pasta." There are some sensory preferences as well: Lee does not like cold food and avoids it at all costs. This is a particular problem at lunchtime and thus partially explains all of the processed food in his lunch box. Lee also does not like the texture of corn and will not eat it. Other than fish, Lee does not have any particular food dislikes. When asked about fruits and vegetables, his mother noted that he likes bok choy, but that

was the only one she could name. Moreover, bok choy has never appeared in his lunch box.

As soon as his mother picks him up in the afternoon from CSS Lee will request a snack. Though he will typically ask permission to eat when hungry, his mother still feels the need to hide foods from Lee to avoid his overeating. She will leave out those items that he is welcome to consume, including peaches and oranges while the more processed options remain out of reach.

With a BMI of 32.5, Lee is obese. He has been diagnosed with high cholesterol that is being treated through diet rather than medication. His mother indicated with pride that her son is on no medications at all and that this was a conscious decision. Other than high cholesterol and obesity, Lee also suffers from occasional eczema.

Lee has no particular oral motor issues. He is independent with a spoon and fork but does not use a knife in the house; meats and such are cut-up for him. His mother expressed surprise when told that he uses an adapted knife with some skill during the *Active Engagement* sessions. Lee can pour his own drink and make a simple snack.

When asked to describe his diet, his mother proposed "high carb" in acknowledgement of the fact that Lee strongly prefers highly processed foods and that most of his meals consist of pre-packaged items.

9.5.10: Mate

Mate is a 22-year old male who with Fragile X Syndrome (ASD).[20] He lives at home with his mother and older sister; his father died recently though Mate does not

[20] Fragile X Syndrome is a genetic variant of autism that results in a range of developmental problems including ID, hyperactivity and anxiety. As per usual, social interaction is impaired.

seem to be mourning excessively, or at least does not verbalize it. The family has just moved into a new home and there are boxes everywhere during the interview. Mate has been an enthusiastic participant in *Active Engagement* with highly social tendencies – he is always the first person to request a song or point out someone else's salad. He now takes tremendous pride in his salads and works quite independently.

His mother indicates that Mate's diet is varied and that he "eats everything." When he was younger, she said that she worried about his overeating but she believes that it is now relatively under control. She remembers that as a child Mate often ate so fast, that he would gag or even vomit. As he has matured into adulthood, however, his pace of eating has slowed down and she no longer feels that it is a serious concern.

Mate has no particular oral motor issues though he often has indigestion after meals. His mother says that he will not verbalize (and perhaps cannot verbalize) his condition but that it is indicated physiologically by body twitching. On those occasions when she notes this behavior, she will remind his to take an antacid.

When asked what foods that Mate does not like, his mother cannot think of a single one. He and his mother and sister all eat their meals together. He independently uses all eating utensils as well as all of the cooking appliances in the home; his mother does not supervise him in any way in the kitchen.

Mate is very open to food but his personal preference when asked, is for carryout meals. If hungry, Mate will simply wander in and make himself a snack, which is typically a hotdog or cup-a-soup. With a BMI of 33.4, Mate is obese. This excess

weight is not due to polypharmacy as his mother has him on no medications at all except over-the-counter items for constipation, indigestion and occasional sinus problems.

When asked to describe his diet, his mother said "balanced." She clearly views her son as an adult, albeit with some social deficits, and does not believe that she needs to micromanage his eating behaviors at this point in his life.

9.5.11: Yvonne

Yvonne is a 21-year old women with ASD. She lives at home with her older brother (who has Down's Syndrome), her younger sister and mother; her father died several years ago. Yvonne is new to *Active Engagement* but has learned the routines and rituals of the class quickly. It is noted that after making herself a large salad, she will often eat the entire bowl, despite the fact that she is reputed at CSS to be a very poor eater.

Her mother says that Yvonne never really had any significant eating problems as a child in terms of what she was willing to eat. She was, however, relatively non-compliant in terms of mealtime behaviors. Applied Behavior Analysis (ABA)[21] has changed this and contributed greatly to Yvonne's ability to attend to meals and participate appropriately. Mealtimes are relatively peaceful now although Yvonne will get up from the table frequently and wander away. Because she does not do this outside of the home, the family is able to eat out at restaurants occasionally.

Yvonne is particularly fond of carb-rich foods and her mother believes that she is particularly susceptible to cravings for such right before her period. Her mother does not

[21] ABA, or behavior modification, involves the use of operant and classical conditioning to make children with challenging behaviors more compliant.

keep any candy in the house because Yvonne will devour any if she finds it. She does provide Yvonne with goldfish crackers, a holdover reward from the period she was in ABA.

Yvonne does not like green foods, particularly vegetables, and will even avoid a cracker if it has a green hue. Her mother expressed surprise when told that Yvonne makes and consumes a large salad each week composed of numerous green ingredients. Outside of vegetables, Yvonne has a wide range of foods that she is willing to partake at home.

Yvonne's mother is from Thailand and likes rice at mealtimes; Yvonne actually prefers pasta. Yvonne is lactose intolerant and so her mother supplies her with soy cheese and alternative dairy products that Yvonne accepts without complaint. At meals Yvonne is very quick eater unless there are non-preferred items on the table and her mother demands that she eat them; in these circumstances she will slow down her rate of consumption considerably.

Yvonne can feed herself with spoon and fork but does not use a knife at home. She can drink from a cup but not pour into a cup. The only snack that she can prepare independently is bread with peanut butter spread on it. When hungry Yvonne will go hunting in the pantry for items that she prefers. She will take these to her mother and mutely request permission. She does not eat anything without the approval of her mother. With a BMI of 35.4, Yvonne is now morbidly obese.

Yvonne has had a long history of GI issues, particularly GERD, constipation and proctitis.[22] Her mother believes that the symptoms of her various GI ailments get

[22] Inflammation of the lining of the rectum.

progressively worse as her period approaches. Yvonne is prescribed numerous medications for these GI symptoms but currently takes no medications for any of the autism related behaviors, including seizures that were diagnosed when she was in puberty.

Her mother notes that, due to several medications that she is prescribed, Yvonne has a harder time perspiring and so extreme heat can be dangerous for her. Yvonne does not drool or bite, but will choke on the occasions where she stuffs her mouth too full; it someone does not intervene she is capable of eating to excess and vomiting.

When asked to describe Yvonne's diet, her mother replied "Ok." But she was quick to admit that when Yvonne is left to her own devices, she will quickly over-consume. Yvonne does not have the ability to understand when she is full, or sensory abnormalities do not allow her to understand the sensation of fullness.

9.5.12: Russell

Russell is a 28-year old male with ASD. Russell has lived in a CSS residential facility for several years; he is an only child to aging parents. He is relatively new to *Active Engagement* and takes his session in a one-on-one environment, primarily due to schedule constraints. He loves salads so the challenge is helping him to develop the skills to be independent in construction. Russell loves choice and is always delighted to look through the ingredient list.

Russell's mother reported that he has had very few eating problems during his life. As a baby he nursed easily and has always had "reasonable" variety in his diet. She did concede, however, that when exposed to foods that he enjoys tremendously, he will eat so fast and to such excess that he will sometimes vomit. Russell enjoys most foods,

but is particularly fond of salad, pizza, and calamari. His mother believes that it is the salad dressing (rather than the vegetables) that Russell most enjoys with salad because there have been numerous times in her kitchen that she has caught him drinking salad dressing straight from the bottle. When asked, his mother cannot name any foods that he does not like.

Possible due to polypharmacy, Russell is often thirsty and drinks large amounts of water and other fluids. During mealtimes he is neither a slow nor fast eater unless it is a preferred food, in which case he will devour the item. In those situations both she and the residential staff will have to coach him to slow down.

When hungry, Russell will simply go to the kitchen and take food; he does not seek permission. Since he has moved into a CSS facility, his mother and father have made it a practice to take Russell out to lunch on Saturdays. She said that he eats huge meals on these occasions though she does not believe that he is particularly hungry. More likely, she believes, he just enjoys the exposure to favorite foods.

Every six weeks or so Russell goes through an abnormal sleep cycle of idiopathic origins; she contends that this pathology has never been adequately explained by his health care providers. During these cycles, Russell will either sleep excessively throughout the day or will be up for three straight days. This is clearly disruptive to all involved and has been going on since he was 15. They do not believe that it is related to his medicines as the same patterns have occurred during periods when he was taking no or few medications.

Though Russell enjoys rice, his mother believes that he has textural problems with it because it often causes him to vomit. Other than this, there are no serious oral-

motor issues. He can use utensils appropriately and can pour his own drink. She noted that one of the problems with helping him learn to cook are visual problems with focus (rather than actual vision).

With a BMI of 19.6 Russell is just under the normal range, however as his weight was estimated by his mother this is likely to be inaccurate. In appearance, Russell is painfully thin.

9.6: Patterns

9.6.1: How individuals indicate hunger

Table 9-1 How individuals indicate hunger

Name	**How They Indicate Hungry**
Andrew	Nonverbal behavior: Steals food from the kitchen
Lindsay	Verbal: Says "I want…."
Melissa	Physiological indicator: Attitude change denotes blood sugar change
Francis	Nonverbal behavior: Makes it himself, does not ask permission
Rick	Verbal: Verbally expresses what he wants
Caroline	No real snacking in the house; has to wait for mealtime
Sasha	Verbal: Tells her mother and waits to be served; will not independently go into the kitchen
Grant	Nonverbal behavior: Sign language; hands to mouth
Lee	Verbal: Asks for requested food
Mate	Nonverbal behavior: Will make own snack
Yvonne	Nonverbal behavior: Bring food to her mother to get approval
Russell	Nonverbal behavior: Will simply take food from the kitchen

How individuals communicate their hunger is highly indicative of the philosophies towards food in their residential household. All of those addressed in this study are adults, yet many participants continue to seek permission for food items, typically because they have limited ability to regulate their own intake. Though some of the young adults discussed in the interviews were compliant regarding food, other participants simply took at will; "steal" was the term used by many parents. Several of the participants are actively involved in food preparation in their home environment and thus are responsible for their own consumption.

As these individuals continue to age and settle into adulthood, it will be important to help them develop skills that allow them to better self-monitor their intake. Within the context of the home environment, their approaches to snacks make complete sense to their parental caregivers. They will need, however, more socially acceptable ways to request food as they move into the community. The primary strategy for all in this population should focus on developing independence within the kitchen so that simple snacks or food collation is an option for all. This process allows independence in the kitchen, provides exposure to new foods, and creates a strong conduit for expressing choice, a powerful tool when working with this or any population.

9.6.2: Food Likes and Dislikes

Table 9-2 Food Likes and Dislikes

Name of Participant	**Foods Likes**	**Food Dislikes**
Andrew	Tuna Seafood Steak Salad French fries	Peppermint Blue cheese Pepperoncini
Lindsay	Macaroni and Cheese	Tomatoes

	Salty snacks White rice White bread Potatoes French bread Pizza	
Melissa	Everything	Nothing
Francis	Chips Cookies Gummies Macaroni and cheese Pizza Hot dogs	Yogurt Vegetables Fruit
Rick	Yogurt Pizza French Bread Cheese (mozzarella) Coffee Lemons	Eggs Beef Pasta All vegetables except carrots
Caroline	Meatloaf Mashed potatoes Chicken Brownies	Lettuce Currently avoids sweets
Sasha	Rice Pizza	Currently avoids sweets
Grant	Macaroni and Cheese Pizza Fries	Radish
Lee	Pasta Chicken Soup (with noodles) Bok choy	Fish Cold Food Corn
Mate	Chips Soda Pears Hotdogs Greens, salads	None
Yvonne	Nuts Snacks Goldfish Candy	Rice Watermelon Green foods
Russell	Salads Pizza Calamari	None

Not surprisingly, most of the food preferences of these young adults (and as noted by parents) are energy dense and often highly-processed foods. Pizza was probably the most common item though there was a tremendous range; no two individuals were the same. Foods that were disliked covered a wider terrain including foodstuffs with strong tastes (peppermint, blue cheese), vegetables (typically bitter), and a range of idiosyncratic choices that likely represent unique sensory abnormalities (such as green foods, cold foods, and eggs).

One of the interesting aspects of food specificity as noted by these parents is that their child's food preferences were not static. Instead, such partialities are often experienced as either cycles or phases with no explanation as to why one food goes out of favor and another is ascendant. This rotational behavior has been noted in other studies addressing eating patterns on the spectrum (213).

9.6.3: Height, Weight and BMI

Table 9-3 Height, Weight and BMI

Participant	**Height**	**Weight**	**BMI**
Andrew	5'8"	150	22.8 Normal
Lindsay	5'6"	168	27.1 Overweight
Melissa	5'0"	140	27.3 Overweight
Francis	5'10"	215	30.8 Obese
Rick	5'11"	230	32.1 Obese
Caroline	4'11"	140	28.3 Overweight
Sasha	4'7"	101	23.5 Normal
Grant	5'10"	172	24.7 Normal – High
Lee	5'9"	220	32.5

			Obese
Mate	5’8”	220	33.4 Obese
Yvonne	5’3”	200	35.4 Morbidly Obese
Russell	5’11”	140	19.6 Underweight

As individuals with autism enter their young adult years, it is clear that patterns of overweight and obesity are already becoming apparent. The data represented here is likely to be conservative given that height and weight were not directly measured, but reported by parents. In many cases the children no longer reside in the family home so the parents have even less insight into the current weight status of their child. Moreover, taking weight of individuals with autism is difficult since they often cannot cooperate, and thus is typically done infrequently.

It should also be note here that studies of ID and DD population based exclusively on BMI have been found to be less accurate than research utilizing anthropometric measurements (as well as, or in lieu of, BMI). Specifically, research based on anthropometric measurements found greater body fat in those with ID or DD than studies that utilized BMI exclusively (27, 394). Thus, BMI has yet to be demonstrated as an accurate tool for assessing the nutritional status of those with disabilities.

A full and complete nutritional assessment incorporating dietary intake studies, anthropometric, biochemical, and clinical assessments has rarely been available for this population primarily because data collection techniques are not suitable at present. This remains one of the primary roadblocks for including adults with ASD, DD and ID in national surveys, such as NHANES.

9.6.4: How parents described their child's diet

Table 9-4 How parents described their child's diet

Name of Participant	**How Parent Described their Diet**
Andrew	Healthy No junk Snacks with fiber No more than 2 servings
Lindsay	Reduced options of late
Melissa	Well balanced
Francis	Poor
Rick	Varied: some good, some bad
Caroline	Pretty healthy
Sasha	Healthy
Grant	Highly controlled; varied
Lee	High Carb
Mate	Balanced
Yvonne	OK. But not good if let to her own devices
Russell	Good

Objectivity regarding diet quality is difficult to achieve, particularly in reference to a parent assessing a child. The patterns demonstrated in this essay are all behaviors of a long-standing nature, and parents were often loathe to introduce change. In sum, parents have to pick their battles. Francis's mother, for example, acknowledged the poor quality of her son's diet and made clear that this was an area where she had long ceased to invest energy. Instead, she chose to focus on ensuring that Francis was physically actively. Consequently, he was one of the few participants who had regular cardiovascular activity in the form of jogging and community-based sports groups.

Other parents demonstrated strong defensiveness regarding their child's eating patterns, despite the fact that the researcher strove to create a nonjudgmental dialogue. Because parental objectivity regarding diet quality is uncertain, it has to be considered as another of the factors when developing appropriate interventions.

9.6.5: Areas of Parental Food Concern

Table 9-5 Areas of Parental Food Concern

Name of Participant	**Parent's area of food concern**
Andrew	Diet soda: his mother indicates they are trying to move away from these at present
Lindsay	Weight driven concerns
Francis	Poor quality and variety Does not like to drink water
Caroline	Slowness in eating
Sasha	Slowness in eating
Grant	Pica
Lee	Eats too many carbs
Mate	Likes carryout too much
Yvonne	High preference for energy dense foods; low preference for vegetables
Russell	Eats so fast, induces vomiting

Across the range of *Active Engagement* participants, rapid eating was highly prevalent. Indeed, of the nine participants with ASD diagnoses, 6 were reported by their parent to have demonstrated this eating pathology. Parents of Lindsay, Rick, Grant, Mate, Yvonne, Sasha and Russell all noted that at some point in time their child had eaten so fast, and to such excess, that they had vomited. Most noted this pattern occurred primarily with foods that were highly preferred and suggests that impulse control plays a strong role in this behavior.

The risks of rapid eating are numerous and include aspiration, indigestion, and, in the failure to reach or appreciate satiety, weight gain leading to possible obesity (395). Moreover, such behavior is socially unacceptable and contributes to the social isolation that defines this population. Typical strategies for addressing this pathology usually involve having an individual present to actively coach a reduction in the spacing of bites (396). New more innovative strategies utilizing technology have incorporated the use of

a vibrating pager to cue consumption cues at fixed intervals. This approach has been found to decrease the rate of eating in teenagers on the spectrum(397) but is not a strategy currently in widespread use.

The two individuals with Down's Syndrome exhibited contradictory behavior as they were exceptionally slow eaters – which caused its own unique stress for family mealtimes.

9.6.6: Formal Diagnosis

Table 9-6 Formal Diagnosis

Participant	**Formal Diagnosis**
Andrew	Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS) Obsessive Compulsive Disorder (OCD) Anxiety
Lindsay	ASD OCD Dermatitis & Eczema
Melissa	Schizophrenia (since 2011) Developmental Disabilities Speech Delays
Francis	ASD ID Anxiety Delayed Speech
Rick	ASD OCD Bipolar
Caroline:	ID: Downs Syndrome
Sasha	ID: Downs Syndrome Hyperthyroidism
Grant	ASD Apraxia Sensory Integration Disorder Pica
Lee	ASD High Cholesterol Eczema
Mate	Fragile X Syndrome (ASD) OCD

Yvonne	ASD Seizure disorder GI problems
Russell	ASD

This list is likely incomplete given that comorbidities are common in this population and secondary conditions often are not formally diagnosed following a primary diagnosis of ASD (37; 38; 39). For example, anxiety and Obsessive-Compulsive Disorder are two conditions that often present in this population (398, 399) and which are commonly treated even in the absence of a formal diagnosis. Anxiety in this population is typically addressed through pharmacological approaches though psychosocial treatment modalities have been applied to high functioning individuals on the spectrum (400).

The relationship between ASD and OCD is more complicated given that behaviors related to both conditions will often overlap. It has recently proposed that the two conditions are situated as divergent pathways leading to shared compulsive behaviors based on unusual sensory interests (401). Treatment of OCD in the ASD population is typically achieved with selective serotonin reuptake inhibitors (SSRI) antidepressants such as Prozac, Luvox, Paxil and Zoloft. Cognitive Behavioral Therapy has also been used to some positive effect in high functioning individuals.

Other common comorbid conditions include epilepsy (17, 41, 97-100), sleep disorders (particularly insomnia and obstructive sleep apnea) (99, 101), motor impairment (99, 102), obesity (42, 103-109), hypertension (18, 110), high cholesterol (19), as well as gastrointestinal issues (111-113) and respiratory, food and skin allergies (41).

Many of the variations in autism diagnosis have been addressed with the new application of Autism Spectrum Disorder, which focuses on the centrality of the core communication deficits rather than the distinctions between the differing conditions. Indeed, practitioners can rarely distinguish between such formal diagnoses as Rett's Syndrome, Fragile X Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified and Autism.

9.6.7: Medications

Table 9-7 Medications

Participant	**Medications**
Andrew	Zyrtec
Lindsay	Seraquil Fluvoxamine Prozac
Melissa	Risperadol Lithium
Francis	Risperidone Paxil
Rick	Seraquil Silexa Levothyroxine Lactulose Metamucil Colace Metatone Chloropromia Diazepam Lamotrayne Citalopram Thorazine Lithium Depecote Risperidone
Caroline	Flonase (allergies)
Sasha	Methiamzole
Grant	Nizoral Benzoyl Peroxide Cordran Tape Thorazine

	Gabitril Ativan Valium Benadryl Zoloft Imodium Mlant Milk of Magnesia Bacitracin
Lee	None
Mate	Over the Counter (constipation, gas, sinus medications)
Yvonne	Lamictal (seizures) Zonegran Miralax Prevacid AC Zyrtec Allergy meds
Russell	Depecote Risperidone Ambien Levothyroxine (thyroid medication) Omega B supplement *Sleep-Thru* supplement

A review of Table 9-7 makes clear that many of the *Active Engagement* participants are on extensive numbers of medications; likewise, several are on almost none. The interaction of medications, the physiological consequences of a heavy pharmacological load, and the effect over the lifespan are incompletely understood. Likewise, for certain conditions (i.e. anxiety, OCD, and sleep disorders) there are almost no behavioral programs for lower functioning individuals on the spectrum and, thus pharmacological interventions are the only treatment option.

The understanding of the adult trajectory of autism is only now becoming the focus of research interest. The consequence of this vast array of pharmaceutical options

as well as their effect on nutritional status, appetite, and manifestation in eating disorders are topics of tremendous interest.

9.7: Discussion: Strengths and Limitations

Parent interviews undertaken for this project confirm the general understanding (though not highly studied) in autism research that eating pathologies continue unabated into the adult years. No parent who participated indicated that their child simply outgrew their food related disorders. In some cases, disordered eating was altered in new ways during the progression through the life cycle. Though as some problems dissipated, others emerged.

For most of the parents interviewed for this project, food was a predominant source of conflict and stress in the household. Yet, across all of the participants of *Active Engagement* food pathologies varied greatly and no two family histories were alike. Indeed, *unique sensory abnormalities feed unique eating disorders*. To be sure patterns emerged: self-selectivity, rapid intake, color and texture preferences, behavior rigidity. But each dinner table was a distinct mélange of sensory abnormalities, autistic expression and parental strategies.

The autobiographical accounts of high functioning individuals are an immensely powerful testament to these eating disorders. These authors, both autistic and literate, are able to describe their food regimes given the vocabulary of the sensory deficient. Many developed elaborate rules, prohibitions and rituals related to mealtime. Most of their behaviors seem somewhat bizarre from an objective perspective, but make some sort of sense when viewed through the distorted perspective that is autism (343).

Donna Williams, a high-profile autistic and advocate wrote in her autobiography (402):

> …I became afraid of eating food, too. I would eat only custard, jelly, baby-food, fruit, lettuce leaves, honey and white pieces of bread with multicolored "hundred and thousands" sprinkled on top, like the spots of color in my dream. In fact I ate the things that I like to look at and feel or that had nice associates for me more than anything else. Rabbits ate lettuce. I loved fluffy rabbits. I ate lettuce. I loved colored glass. Jelly was like that. I loved jelly. Like other children, I ate dirt and flowers and grass and bits of plastic. Unlike other children, I still ate flowers, grass, bark and plastic when I was thirteen years old. As a teenager, the old rules still applied. If I liked something, I would try to lose myself in my fascination for it. Things, unlike people, were welcome to become a part of me.

Despite the *strangeness*, Donna William's behavior had a purpose: she used food to make sense of her world. Following those on the spectrum into their interior selves is usually not possible. But, there is now a better understanding of how food (the size of bolus, texture, flavor, color, and shape) can affect eating patterns for this population (403, 404). A greater appreciation of these variables will, in turn, contribute greatly to an objective understanding of the eating behavior of this population.

The interviews included in this chapter make clear that children with autism do not simply outgrow their eating problems. Some of the individuals discussed herein modified, shed or added dimensions of their pathology during their progression into young adulthood; none were "cured". How these behaviors will manifest in the full maturity of adulthood is unknown at present, which is consistent with the overall murky picture of adults on the spectrum.

Whatever direction research on adults with autism proceeds, it is vital that the parental perspective be included. In studying a condition with tremendous heterogeneity

and many unknowns, the best source of information will remain parents, as this analysis of feeding histories has demonstrated. Consequently, forming an authentic dialogue with caregivers is going to be vital to helping those with autism traverse the bridge into adulthood.

The strength of this case study using thematic analysis is this very reliance on the parental voice as well as the fact that it calls attention to eating disorders from a developmental perspective, which is rarely done. The limitation of this study is due to the necessity of breaking down tremendous amounts of raw data into comprehensible categories. Future iterations of the project might adapt this source of data collection for different interpretive techniques such as content analysis.

Chapter 10: Conclusions and Lessons Learned

Active Engagement output generated the following in support of the articulated aims of the research:

a. Defined the supporting materials, references, adaptive tools, technology, and approaches that are needed to develop a health promotion for young adults with autism;
b. Provided a ethnography of the differing path by which individuals participated and passed through the process;
c. Created a case study addressing the pain response and behavior change for one participant;
d. Addressed the ways that eating disorders carried over into the adult years through a case study using thematic analysis; and
e. Generated new hypotheses as to the most successful means of developing food preparation skills for individuals with autism and other intellectual disabilities.

10.1: Confirmation of study aims

10.1.1: Aim 1

Aim 1: To explore the feasibility of health promotion program based on the development of cooking skills for young adults with autism. This aim is based on the understanding that the development of cooking skills contributes to the enhancement of dietary quality and variety. It was hypothesized that that the development of cooking skills among young adults with autism would greatly contribute to a change in health related behaviors, including enhanced dietary variety, in this case with fruits and vegetables. It should be noted here that *Active Engagement* methodology had no explicit method for assessment of increased consumption of specific fruit and vegetable items due to the fact that the program was designed for a natural setting, rather than a clinical one.

Consequently, there was no capacity to assess each bite taken by each participant in the social setting of the *Active Engagement* classroom. But the unstructured observations addressing overall participation did allow for an assessment of skill development and class immersion.

These observations, grounded in participant observation, describe a setting that offered regular and systematic exposure to a wide variety of fruits and vegetables. Given a high level of choice and over six months of opportunity, almost all of the participants ultimately became willing to partake of their own salad. Some individuals made dramatic changes in consumption patterns, while others made more modest adjustments by simply allowing new ingredients into their salads.

10.1.2: Aim 2

Aim 2: To develop the skills necessary for cooking as a collective learning process (autonomy, self-efficacy, preference and social-relatedness) among young adults with autism. It was hypothesized that these skill sets would be developed during the progression of the course and this was demonstrated to be true. Moreover, as Chapter 7 demonstrated, the rate and level of skill set advancement was highly individualized. Autonomy was demonstrated in the increasing individuality of the salads produced and in the decisions made to support this. Self-efficacy was established in the development of salad production skills. The realm of social relatedness was situated as the skill set with the most startling gains as it became clear that *Active Engagement* participants were clearly influenced by the actions of those around them, which was typically expressed in behavioral imitation. Through participant observation, the researcher was able to note how the actions of individuals were copied, ingredients waxed and waned in popularity,

and trends swept through the kitchen classroom. While such behavior would be expected among neurotypical adults, it was intriguing to observe in individuals with several social deficits.

Though autism was once seen in terms of profound and universal social unresponsiveness, this understanding has given way over the last several decades to a more nuanced interpretation. Indeed, it is now accepted that there are a wide range of social phenotypes on the spectrum that find expression in a myriad of ways. Moreover, successful enhancement of social skills for this population have been noted in a variety of structured settings where the strengths and weaknesses of the individuals involved can be specifically addressed (405).

Given the supportive environment and the individualized approach of *Active Engagement*, the resulting imitative behavior demonstrated should be seen as inevitable. Peer modeling was not a tool deliberately applied in the progression of the course, but it developed into a powerful one. It should be also noted that there were also negative aspects to social imitation. Individuals who were disruptive caused tremendous stress to other participants and seating arrangements had to separate those individuals who most typically clashed.

After noting the strong social forces at work during the class progression, the researcher was quick to make use of the phenomenon by directing participants to what their peers were doing, what was different and innovative. Moving forward, it might be appropriate to utilize a speech therapist during *Active Engagement* sessions so as to optimize socialization opportunities and to enhance opening and closing of circles of communication.

10.1.3: Aim 3

Aim 3: To give voice to those with autism who, because of communication deficits, cannot participate in research via traditional methods such as interviews or surveys. It was hypothesized that an ethnographic approach, or qualitative analysis, would provide a powerful tool for the privileging of voices with communication disorders. This study has utilized a variety of means to explore many different stories within the progression of *Active Engagement*. In so doing it is argued that this is the most appropriate technique for capturing the behavior of a heterogeneous population and provides compelling information about the ways those with autism move forward in the face of their sensory abnormalities.

10.2: Summary of main findings:

In the final analysis, *Active Engagement* is demonstrated as an effective program for the development of cooking skills and the enhancement of dietary variety in young adults with autism. The combination of these two distinct outcomes – learning to cook accompanied by increased dietary variety -- situates the program as a blended intervention combining health promotion with life skills education. In sum, it is program framework specifically suited to this at-risk and underserved population.

While *Active Engagement* provides an over-arching structure for the program, no two participants made the same journey through the weekly classes. Indeed, each individual passed through the program with a unique trajectory built on individualized techniques, tools, and methodologies. Consequently, the outcome analysis is qualitative with an emphasis on the heterogeneity of the response.

For these reasons *Active Engagement* should not be regarded as a curriculum, a simple road map by which to direct this population to the acquisition of cooking skills and dietary variety. A step-by-step approach to teaching any topic to individuals with autism is not appropriate given that the wide behavior diversity of the population would require a highly complex rubric that would quickly become impractical (266). For this very reason, it is rare to see interventions for individuals on the spectrum verified by randomized controlled trials. Approaches of that type require measurement of discrete units of analysis but, like many other learned abilities, cooking is a dynamic process involving many interacting skill sets.

Relying on qualitative data analysis to demonstrate efficacy, *Active Engagement* offers a structured approach that identifies both the strengths and weakness of each participant and works within this individualized framework to achieve skill competency. While there is no single representation of how *Active Engagement* is experienced, there are overarching conclusions about the program and defining principles for the establishment and implementation of nutritional interventions for young adults with autism. What works? What doesn't?

These conclusions, accompanied by an ethnographic analysis of the class trajectory, a case study analyzing parental attitudes about eating habits for young adults with autism, and an in-depth exploration of the pain mechanism in hyposensitive individuals complete the interpretation of data. Accompanied by the electronic tool kit that is stored in www.AutismCooks.com, (see Figure 10-1) the output of *Active Engagement* is demonstrated to be a significant and creative contribution to research on young adults on the spectrum.

Examination of the adult years on the spectrum is only just beginning and there is much to learn across many domains of research. *Active Engagement* has made clear that, in an environment attuned to their unique range of sensory abnormalities, adults with autism will participate in their own food preparation with enthusiasm. The modifications necessary to build an appropriate and enriched learning environment with minimal stress are the basis of the researcher's conclusions and are discussed below.

Figure 10.1: Screen Capture of www.AutismCooks.com

10.2.1: Conclusion #1: Fruit and vegetable consumption are different behaviors

Active Engagement participants demonstrated strikingly different patterns of fruit consumption when compared with vegetable intake. As data collection was done primarily via field notes, pictures, and interviews, it should be noted that fruit and vegetable consumption was not specifically measured. Participant observation by the researcher revealed that, in general, individuals were far more willing to consider eating

new fruits than vegetables and were more far more enthusiastic about any fruit consumption (whether familiar or not) given only the most superficial exposure. Typically having an individual simply slice their own fruit was enough incentive to encourage intake, and accompanying ingredients or coaching were rarely needed.

Vegetable consumption, on the other hand, was nested in far more mitigating and confounding factors and was heavily influenced by texture, color and accompanying toppings. Fruit consumption could be enhanced with relative ease but vegetable intake required the highly supportive environment created by *Active Engagement.* It was noted on numerous occasions during class sessions that individuals were far more willing to try a new vegetable (i.e. iceberg lettuce, mushrooms) after they saw others participants enjoying it. Samir requested mushrooms from the researcher and they were rotated into the inventory; watching her prepare and consume them inspired others to try them. Such visual inspiration was not necessary to induce participants to try a new fruit.

There has been significant research on the multifactorial nature of motivators involved in food choices but certain forces, such as availability, sensory preferences, satiety and social transmission, are better understood than others. It is widely hypothesized that the preference for sweet tastes is an instinctive evolutionary response, while the avoidance of bitter tastes (typical of vegetables) is likely protective.(406) Consequently, differential consumption patterns between fruit and vegetables makes sense across all populations, not just young adults with autism.

Previous research addressing consumption in the general public has already made an effective argument for distinguishing fruit from vegetable consumption as separate eating patterns with "different antecedents" (192) and unique motivators. Likewise,

Gibson et al. concluded that among typically developing children consumption of fruits is related to different psychosocial and environmental factors than consumption of vegetables (407).

The practical consequence of this distinction when working with adults on the spectrum is that introduction of fruits into the diet can be more far more direct than that of vegetables. For example, fruits can be introduced in a snack context, where the fruit can stand by itself as an item to be consumed. Vegetable consumption, on the other hand, requires greater individual involvement, a more supportive environment, and tremendous attention to individual sensory abnormalities. Vegetables are rarely considered (by themselves) as appropriate for a snack and usually have to be situated – at a minimum -- as a side dish.

Dietary enhancement of vegetables has been demonstrated in *Active Engagement* to require a far larger investment of materials, time and participant involvement. Separating fruit from vegetable consumption offers potential for the development of both behaviors.

10.2.2: Conclusion #2: The community context of the program is critical

One of the key factors, wide base of support that *Active Engagement* enjoyed at CSS was the participation– and enthusiasm – of aides and staff. Though serendipitous, the program participants included both aides and clients which ensured that the entire CSS campus was aware of the *Active Engagement* activities. Further, having aides make their own salads during the class period ensured that their clients had greater independence during the class process. With aides occupied, those with autism were forced to develop their own salad making skills, rather than merely rely on their aide for

continual assistance. For the young adults on the spectrum *Active Engagement* was a nutritional intervention, but for the large population of CSS it also served as a wellness program.

In May (for National Salad Month) and again in August, assemblies were held for the entire CSS community in the gym. Here *Active Engagement* participants produced and served their salad creations, while wearing stickers that asked and answered the question "Who makes the best salad in the world? *I do*!" These events, and the surrounding publicity, went a long way towards the development of participant pride in *Active Engagement* and helped cement it as a community-based program.

10.2.3: Conclusion #3: Promotion is effective

Instructor promotion of techniques, ingredients or combination of ingredients was found to be a particularly powerful way to influence behavior during the *Active Engagement* sessions. When done with a high affect (excited and enthused tone) it was typically a productive means of gaining the attention of the participants and simultaneously brought their gaze (and sometimes their curiosity) to the item at hand.

Example:

Researcher: (*dramatically holding up a red pepper*) "Miss Janice has red peppers today. They were on sale at the grocery store and I bought lots and lots of them! They're delicious and they taste red.

Participant: Taste red?

Researcher: Yes. Close your eyes and take a bite. You will taste red.

Promotion of ingredients in this manner was not always successful in moving the individual to preference, but it did contribute greatly to increased willingness to try new ingredients and also built up the overall sense of entertainment in the class. Moreover, the use of promotion helped to encourage social interaction. The individual exposed to the promotion might not be willing to taste the item in question, but would have the opportunity for interaction and expression as to preference.

Example:

Researcher: (*dramatically holding up a red pepper*) "Try a pepper?"

Participant: No, thanks.

Researcher: Why not?

Participant: I don't like seeds.

Researcher: Ok. Thanks for telling me.

Future use of promotion might draw on seasonal variation to highlight produce as well as to incorporate those items that emerge from the CSS gardens. Garden to table themes, for example, might offer powerful teaching opportunities.

10.2.4: Conclusion #4: The first line of treatment in eating disorders is behavioral

Though more extensively studied in children on the spectrum, eating disorders among adults with autism are typically regarded as primarily behavioral, (167) rather than biochemical or mechanical. Behavioral eating disorders incorporate two domains:

a. Aversive eating: includes self-selectivity, food refusal, choking, gagging, and

expulsion; and

b. Sensory-based feeding problems: reference textural and color aversions.

It is hypothesized that these patterns on not based on an innate chemical or physiological needs but rather the need for sameness and routine that is manifested across the entire spectrum (167).

How to address eating rigidity from a treatment perspective? Across research addressing children on the spectrum, it has been found that the use of choice -- whether in objects or activities -- is an effective mechanism for promotion of increased on-task behavior (408), compliance (409), and adherence to educational activities (410). Moreover, use of choice has also been correlated with a decrease in maladaptive and challenging behaviors (411, 412).

Use of choice as a treatment strategy greatly contributed to gains across all skill sets addressed in *Active Engagement.* Choice was utilized explicitly in reference to ingredients, textures, activities and tools, but it was implicitly offered in other ways such as where to sit, which bowl to use, and the order in which the individual could acquire ingredients. Through these means, choice was exploited as an intervention tool and participants were continually reminded that though all participants began with the same ingredients, all of the salads produced were quite distinct. A display of the extensive array of ingredients (both in visual layout on the counter and in a workstation pictorial inventory) also contributed to this strategy.

It should be made clear that choice was not simply the presence of an adequate inventory of ingredients but, instead, a conscious strategy of emphasizing options over

limits. Given the unique and widely manifested sensory abnormalities within the population being addressed, choice became a conscious way to evade the need for self-selectivity and to encourage individuality. More research is needed on the use of choice for treatment of eating behaviors in this population but *Active Engagement* has demonstrated that this technique shows much promise as an intervention strategy.

10.2.5: Conclusion #5: Individual sensory abnormalities feed individual sensory eating disorders

If the first line of treatment for eating disorders on the spectrum is behavioral, it is certainly not the last. When individuals are resistant to options of choice, it often becomes necessary to acknowledge that the highly individualized sensory abnormalities that define autism are likely to contribute to individual sensory disturbances that are subsequently manifested in food preferences.

Elsewhere in this research, it is has been demonstrated that abnormalities in sensory factors (i.e., smell, texture, color, and temperature) likely contribute strongly to food selectivity in this population (45, 194, 199, 200) though medical conditions (204), pharmacology and physical issues, such as oral motor development, may all contribute to these eating pathologies as well. Teasing the nature of these relationships is important if for no other reason that it acknowledges the foods that will be unpalatable (and therefore unacceptable) to individual participants, rather than simply an expression of behavioral rigidity.

A complete exploration of the manifestations of sensory dysfunction in this population is beyond the scope of this research, but it should be noted that these pathologies are so ubiquitous that some researchers have argued that such should be

considered diagnostic (413). Moreover, these abnormalities are seen across the lifespan and across the range of severity of the condition.

Research and autobiographies of high functioning individuals on the spectrum shed tremendous light on the issue of sensory issues with food. Given the ability of this population to fully articulate the ways food fed their sensory deficits provides great insight into this issue. Stephen Shore, now a professor and autism advocate, remembered:

> Brown or black food wouldn't be eaten as I insisted that they were poisonous. Canned asparagus was intolerable due to its slimy texture, and I didn't eat tomatoes for a year after a cherry tomato had burst in my mouth while I was eating it. The sensory stimulation of having that small piece of fruit explode in my mouth was too much to bear and I was not going to take any chances of that happening again.
>
> Carrots in a green salad and celery in tuna fish salad are still intolerable to me because the contrast in texture between carrots or celery and salad or tuna fish is too great. However, I enjoy eating celery and baby carrots by themselves. Often as a child, less now, I would eat things serially finishing one item on the plate before going on to the next (414).

Identification of a sensory response in the realm of consumption is ultimately based on the skill and experience of the researcher. A general approach that has proven efficacious is to draw on the researchers' own unique sensory abnormalities. Mindfulness of one's own food likes and dislikes can be used as a useful yardstick to ask when '*enough is enough'* and to accept refusal from a participant.

> Example: A young man had refused to eat peppers and had indicated that this was due to the seeds. The researcher responded with a number of different variations and even deseeded peppers before presentation. This was to no avail,

and the researcher concluded that the individual was genuinely aversive due to an individual sensory abnormality. Referencing her own unique sensory dislikes in food, she concluded that she should no longer present him with peppers and acknowledge his stated preferences.

10.2.6: Conclusion #6: Song creates joint attention and contributes to social relatedness and skill development

The use of songs and music with individuals on the spectrum have been addressed in research and have been demonstrated in children with autism to contribute to social interaction (335, 415-417) as well as to the promotion of skill independence (337). Some studies have also found that additional benefits, including mood change and reduction of depression, led to increased self-identification of belonging and social connectedness for high functioning individuals (418). These responses to music are similar to those reported in typically developing populations, and demonstrate how significantly music can impact those with ASD.

One of the most exciting practical applications for this population, however, is in the use of music and song in the establishment of joint attention in educational activities (333, 335). Music used in improvised contexts can also create an individual-centered therapy that can appeal to unique preferences; joint attention emerges as those on the spectrum come to appreciate that the music is referencing themselves. As one review of music therapy on the spectrum noted: "Active music making promotes interest and motivation to a degree that leads to joint attention and tolerance of shared engagement" (333).

While the preponderance of the literature has focused on the use of music in studies with children on the spectrum, *Active Engagement* has demonstrated the efficacy with adults through the use of simple songs during the course progression. In Chapter 8 (Ethnographic Analysis of *Active Engagement*) the researcher explored the ways song was used to introduce social components, teach process, reinforce motion and bring attention to participant behavior. In their totality, song offered one of the most powerful means for creating joint attention during the progression of *Active Engagement.*

10.2.7: Conclusion #7: While multiple skill sets were taught, the primary goal was engagement

Active Engagement is based on the development of four specific skill sets (self-autonomy, self-efficacy, social-relatedness and preference). During the progression of the course it was necessary for the researcher to continually adjust objectives for each individual as needed to ensure continued and realistic progress. It should be noted, however, that before these four skills can be addressed, it was first necessary to engage the participant in the course, to have them invested and willing to participate.

While most *Active Engagement* participants quickly became caught up in the class rhythms, there were several students who simply sought to escape from the class. They typically did this with disruptive behavior that in other contexts might have had them removed from the area, or with elopement. To deal with challenging behaviors such as these, the researcher first worked to ensure that the unique anxieties of each individual were addressed so as to make the classroom experience as enjoyable as possible. Once anxiety had been addressed and the participant became aware that avoidance strategies would not be successful, attending to the class activities became much easier.

Consequently, those individuals who made less progress than others in the acquisition of preference were still well-situated as enthusiastic participants in the class with significant gains in self-autonomy, self-efficacy and social relatedness. From this position, participants could move forward with the remainder of the cooking curriculum (see Table 5-3) and the development of more advanced skills involved in food preparation. For this reason, the main priority of the researcher remained ensuring that individuals were continually engaged and enjoying the class before emphasis was placed on the acquisition of any of the defined skill sets.

10.2.8: Conclusion #8: The researcher was more coach than teacher

The researcher was not positioned in the classroom in the traditional central teaching role, as the primary source of instruction. Instead, the researcher's function was to introduce as well as re-enforce the skill sets involved with salad production. Aside from the technical aspects of salad preparation, two basic ideas were continually coached at all *Active Engagement* sessions:

a. **A salad is a collection of color and texture**
   What specific color and texture was used to make a salad remained up to the individual participant and variations were not only encouraged, they were verbally praised.

b. **If you change the texture, you change the taste**.
   The initial classes began with an initial exploration of texture via "The Carrot Food Map" (See Figure 3-2). After this activity (and participants had tasted each variation), each person was encouraged to experiment with the various techniques on other vegetables. This was reinforced by the instructor through demonstrations as well as calling attention to salad variations noted throughout the class: "Look everyone! Sasha is using her peeler to prepare her celery. Melissa is ripping her lettuce, but Samar is cutting her lettuce into strips."

The participants were told repeatedly "There is no right way to make a salad." And individuals with idiosyncratic contributions were praised as well (i.e., salads with only a few ingredients, or all one color). Consequently, the *Active Engagement* participants did not conceptualize salad in a narrow way, and did not feel that they had to recreate the same salad each week. Salads became an open-ended and creative product that was continually recreated and redefined.

10.2.9: Conclusion #9: The route to enhancing consumption of fruits and vegetables for young adults with autism is directly through preference

Most interventions for individuals with autism have focused on children, and have attempted to enhance variety by nutritional sleight of hand. For example, such approaches have included:

- Direct modification of less preferred foods with condiments (228);
- Use of range of personalized re-enforcers to increase variety (419);
- Re-presentation of expelled bites (233);
- Blending of non-preferred foods into preferred foods (234);
- Differential reinforcement with non-removal of the fork, and stimulus fading to increase consumption of non-preferred food (230);
- Home based treatment of taste exposure, escape extinction (reward of a previous behavior is halted), and fading (prompting gradually withdrawn); (231)

All of these programs were predicated on the idea that a reward-based system is the only means to achieve the introduction of new foods into the diet for individuals with autism. *Active Engagement* is based upon the premise that each individual will build their salad based on personal preference along a continuum of options that address taste, texture, and

color. Self-autonomy and self-efficacy contribute to the ability to experimentally determine individual preference and preference will ultimately lead to greater dietary variety.

Preference as a goal can emerge in many ways. Indeed, several participants developed partiality for their salads at the first session, apparently requiring nothing more than access to fruits and vegetables in order to partake. Others arrived at preference via repeated exposure that involved many factors including watching peers and aides consume, as well as producing their own salad. It can been seen that preference is a complex and nested issue that is ultimately built on highly personal features and can be expressed through a variety of means including:

a. sensory choices: avoiding or seeking out particular textures. Multiple examples made clear that it was not necessarily the ingredient that individuals rejected so much as the texture. For example, broccoli florets were strongly rebuffed by most of the participants but shredded broccoli was popular across the entire population.
b. taste choices: One of the most significant taste choices was in reference to dressing. Ranch (savory), honey mustard (sweet) and Italian dressings were always available and most individuals would rotate through these various dressings. A few participants stuck to one dressing for the duration of the course, and at one point participants began to mix dressings together to create even more options. Toppings were another means to express taste preference. In the beginning, most participants chose every topping available, expressing strong preference for choice in general rather than for any specific ingredient. After

several weeks the participants settled in and chose only the truly preferred items. Protein items were popular among all the students and aides.

c. color choices: It is not uncommon for individuals on the spectrum to avoid or seeking out particular colors in their food palette. The range of colors offered in *Active Engagement* sessions was extensive and included yellow (peppers), orange (peppers, carrots, mandarin oranges, sometimes tomatoes, cheese), purple (shredded cabbage), red (peppers, tomatoes), white (peeled cucumbers, shredded broccoli, eggs, chicken) and many different hues of green.

d. Choice of size: Some individuals would create uniform – almost precise -- portions for their salad, while other participants had erratic and varying sizes. Some enjoyed large vegetable chunks while others preferred tiny minced or diced ingredients.

It should also be noted that the researcher was particularly responsive to requests from the participants regarding new ingredients that they requested. In this way, mushrooms, turkey bacon bits, hard-boiled eggs, chicken and mandarin oranges were introduced. The requests for protein started early in the class and continued to the end unabated. After the introduction of chicken breast, for example, requests came in for new preparation techniques (i.e. breaded rather than grilled). The addition of protein to the salad moves it in the direction of a meal, rather than a side dish but the addition of protein greatly enhanced participant satisfaction with the finished salads and remained, post introduction, a set and very population part of the repertoire.

10.2.10: Conclusion #10: Social forces are very powerful instrument of behavior change in the autism classroom

The project was not originally designed with an emphasis on the social dimension as a catalyst for behavior change. This is in part due to the researcher's extensive experience in working with individuals primarily in one-on-one contexts. Consequently, she neither predicted nor anticipated the means by which peer observation and social modeling would affect course activities and events. When they occurred, however, she did not miss them.

In many ways this references the "aha" movement of *Active Engagement* analysis, or that point in interpretation were unrealized potential is revealed. As one experienced field worker noted: "To come full circle, the tacit understandings gained during participant observation facilitate the intuitive moments when a selection of notes about events, people and conversations comes together to provide us with a deeper insight and understanding of behavior" (325). Coming full circle in this instance referenced the realization that, even in a room full of individuals with systemic and substantial communication deficits, social forces were incredibly powerful.

Moving forward, it will be important to use the social component as a building block, and to design interventions with an acknowledgement of how important the role of human interaction is in the realm of food production and consumption.

10.3: Strengths and limitations

The strengths of *Active Engagement* as a nutritional intervention and health promotion are numerous. First, traditional research has typically focused on an intervention as performed "on" those with autism, rather than "with" them (237). *Active Engagement* was built bottom up with community involvement involving numerous stakeholders. Such community-based interventions for health promotion are ideal for this

population in that they deal directly with specific deficits, alleviate researcher-subject mistrust, and heavily promote sustainability.

Active Engagement was designed and implemented so as to include those individuals with autism that are typically ignored – that is, lower functioning adults with compromised ability to communicate. Typical interventions for those on the spectrum have addressed children with autism or high functioning adults with autism who can more easily define the outcomes.

Second*, Active Engagement* puts the researcher in the position of being a participant observer. In so doing, behavior of the nonverbal is given expression and the different ways that individuals pass through the course are revealed and can be analyzed. In sum, behavior is seen as a form of communication and analyzed as such.

Third, the qualitative and open-ended approach to data gathering revealed behaviors and group dynamics that other methods would have missed. The use of ethnographic techniques offered a means to capture the complex interaction of factors that affect consumption patterns in a population that has significant communication deficits. Fourth, the key skill sets of autonomy, self-efficacy, social-relatedness and preference were supported and developed for the *Active Engagement* participants. This is especially important given that advancement of these domains is vital for this population if they are to live with as much independence as possible during the adult years.

Fifth, another positive aspect of *Active* Engagement is the fact that the program is carried out in a natural setting. Because the program is implemented in a kitchen classroom, rather than a clinical environment, the tools and techniques utilized are characteristic of most home environments. Lastly, *Active Engagement* is highly

individualized and makes use of the individual's food preferences to build skills sets. As with most effective autism programs, the focus of attention lies on the participant strengths rather than weaknesses.

Despite the fact that *Active Engagement* does not offer a set curriculum, it does provide a generalized approach for working with adults with autism. These guidelines are built upon descriptive detail, implied meanings, and a discussion of ongoing processes and concepts in the classroom. This perspective requires the instructor to follow the flow of the participant interaction (rather than lead it) and to honor the unique differences of each individual. Thus *Active Engagement* offers a conceptual model that suggests both active ingredients and treatment techniques that are effective across a range of interventions for this population.

The weaknesses of *Active Engagement* are several. First, as previously discussed, qualitative data collection is considered complete when saturation has been achieved, that is no new behaviors are noted. In a population as heterogeneous as autism, however, new behaviors are continually emerging. Indeed, the *Active Engagement* classes are continuing as the researcher writes this conclusion and new responses to class activities continue to be noted. Consequently, it requires the experience and judgment of the researcher to determine when data collection has been sufficient.

Second, triangulation in data collection for *Active Engagement* would have been greatly enhanced if aides and residential caregivers for participants had been interviewed. The in-depth and semi-structured interviews undertaken with parents provided immensely important and powerful supporting material and it is hypothesized that doing

so with aides would have contributed even more to our understanding of the behaviors of young adults with autism.

Third, *Active Engagement* lacks a quantitative component. To incorporate a mixed-method approach would have required the identification of a single, discrete component for measurement, for example, number of bites, number of food refusals, number of requests for new foods, etc. Such approaches reduce food consumption to a static, discrete and one-dimensional process when it is actually a multidimensional phenomenon at the intersection of numerous pathologies and skill sets for those with ASD. Moreover, most such aspects of consumption are difficult to measure in a social setting, rather than a clinical one.

Attendance, for example, is an appropriately measurable element of *Active Engagement* that contributed greatly to program outcomes. *Active Engagement* participants had very little control over their own ability to attend class sessions as vocational and educational programs pulled them away. Consequently, the meaning and power of this measurement would have been questionable.

A single-subject research design was considered for use. This technique would have allowed measurement of distinct parameters unique for each participant. While commonly used in the field of special education, this approach remains problematical in the context of *Active Engagement* due to the fact that very few behaviors related to consumption are measurable or even discrete. Moreover, such an approach would require a clinical setting, rather than a social group context, as it is necessary to observe the behaviors in question at all times. It was not realistic to have one observer per participant

to continually note the behaviors of interest (i.e., numbers of bites of a particular vegetable).

Fourth, *Active Engagement* lacks a carry-over program at present. One of the most difficult aspects of educating those with autism is helping them to generalize skills; that is, moving a newly acquired ability out of the classroom and into another, more natural, context. The ability to prepare salads is an ideal task for introduction in the home or residential environment and this needs to be a priority as the program evolves and moves forward.

Fifth, at present *Active Engagement* lacks a program evaluation component. With the researcher situated as the participant observer, an internal program evaluation seems to be somewhat problematic. Studying the effectiveness and efficiency of the program would be better served by utilizing input from all of the various stakeholders involved in the implementation of the program including parents, aides, and CSS administrative staff.

Lastly, the use of ethnography and participant observation as a data collection process takes an extended period of time to be done properly. Typically, nutrition education or intervention programs are limited to just ten weeks, due to research and financial constraints. Ten weeks is not sufficient for this population with this type of methodology. Due to sensory abnormalities, individuals with autism need greater expanses of time to adjust, learn, internalize concepts and externalize competence. After all, it is only when the participants ceased learning to construct salads that they began to explore textures, colors and flavor. Creating extended length programs is one of the fundamental shifts that must occur in our thinking of how to create appropriate interventions for this population.

10.4: Implications for future practice

Active Engagement has been found to be an effective program for drawing young adults with autism into their own food preparation process and, in so doing, enhance variety. Success in *Active Engagement* can be observed in numerous realms (autonomy, self-efficacy, preference and social-relatedness) and intervention strategies can address any and all of these, as needed. To move the research beyond this initial investigation, there are several possible directions to proceed:

a. Within the class context: Individuals can advance into classes that offer more hands-on skill sets with cooking since learning to chop, grate, peel and shred are all skills taught in the first, most basic level of cooking (see Table 5-3). Moving those individuals that are ready to the next level would involve the introduction of heat application and involve greater safety concerns. As with salad preparation skills, individuals would progress on their own unique path, based on their own strengths and deficits.

b. Outside the class context: The skills acquired during the course can be transferred into another setting in an attempt to obtain generalization, which could include either a residential or home environment. One idea is to offer a weekend class where parents or residential aides are encouraged to attend with their adult child/client. During this evening class the parents or aides would be "taught" by their child/client about the rituals and procedures of *Active Engagement* so that they would then be in the position to assist in the transfer of the skills into the home environment. It is important that the parents/aide have a very good

understanding of what makes *Active Engagement* successful if generalization of the skill is to occur.

c. Based upon the distinctions made herein between fruit and vegetable consumption, future research on this topic should consider pursuing fruit consumption for this population separately and as part of a snack-based program. Such a platform can be less elaborate, involving only the simple manipulation of a fruit that can be accomplished with both minimal investment and support and thus could reach a far larger population than a class-based program.

d. Another very important way to generalize the skill sets is to utilize the *Active Engagement* website: www.AutismCooks.com as a mechanism for communication. On this website can be found all of the materials relating to the class including handouts, audio files of the songs as well as web links to video files of course activities. The site has the potential for participants to have individual pages on the site (a la Facebook) where they would be allowed to post information, video, comments, etc. Moreover, AutismCooks.com offers the potential for parents and caregivers to communicate with the researcher directly so as instructions regarding carry-over skills from the classroom can be directed into the home environment.

10.5: Final Thoughts

An under-served and at-risk population is worthy of a nutritional intervention. Young adults with autism are a population with demonstrated rates of obesity and overweight. The epidemiology of chronic conditions that typically accompany obesity

are incompletely understood at present for this population but appear to be marked by poor screening, under-diagnosis and poor disease management. Moreover, this population is afflicted by high rates of gastrointestinal issues and almost ubiquitous eating disorders, the most pronounced of which is food selectivity. Concurrently with these various pathologies, the transition to adulthood is marked by a reduction in the challenging behaviors that limit the ability of individuals with autism to fully participate in their education during childhood.

Rendering this period of life (which is marked by the reduction in maladaptive behaviors), more productive makes sense given that these individuals will need to develop as much independence as possible if they are to enjoy the highest quality of life in their adult years. As a merging of life skills with health promotion, *Active Engagement* can foster a change in the participant's relationship with food as well as contribute to an enhanced nutritional status. It also builds the foundation for the development of cooking skills that will serve them well throughout their adult years.

This thesis has attempted to delineate numerous things about the development and implementation of *Active Engagement*. First, the tools, techniques, activities and methodologies needed to create an effective teaching environment for a socially based class were defined. Second, the narrative account of how individuals progressed through the program in unique ways was drawn. Chapter 7 demonstrated that for each skill set and activity developed, a vast range of behavior was demonstrated. Chapter 8 detailed the experiences of Paul, a participant in *Active Engagement*, and showed how an abnormal pain response was manifested during his class participation. Chapter 9 provided a case study using thematic analysis that analyzed interviews with parents to demonstrate

that these young adults with autism did not outgrow their eating disorders during the transition to adulthood. Lastly, this chapter defined the broad parameters for the development and implementation of *Active Engagement* into new contexts with new topics.

Based upon the materials and activities defined herein it is believed that *Active Engagement* provides an important contribution to a population that is only now beginning to get the research attention it so richly deserves.

Appendix A: Parental Interview Form

Parent/Guardian Interview Template Form:
Demographic and Eating Information

Name of Participant
[Son/Daughter/Ward]:_____

Date of Birth _____ **Current Age:** _____

Height: _____ **Current weight:**_____

Currently lives at:_____

Parent/Guardian Name: _____

Parent/Guardian Contact
(phone/email):_____

Part 1. Feeding Information

1. **Feeding difficulties, which are currently problematic.**

   Feeding Problem **When did the problem start?**

2. **Describe feeding difficulties that occurred in childhood.**

3. **Describe the current feeding environment for him/her.**

4. **Describe any behavior problems during mealtime.**

5. **How are feeding behaviors handled?**

6. **Describe any feeding practices.**

7. **Note any foods that he/she likes.**

8. **Note any foods the he/she dislikes.**

9. **How would you describe his/her diet.**

10. **How long does it take for he/she to complete a meal.**

11. **How does he/she indicate hunger?**

12. **Any other information relating to feeding.**

Part 2. Medical Information

1. **Name all formal diagnoses:**

2. **Current medical problems:**

3. **Current Medications that might affect eating patterns**

4. **Does he/she have any food allergies?**

5. **Current Oral Motor Status:**
    a. **Is there any drooling?**

    b. **Are there any biting issues?**

    c. **Does he/she choke often?**

    d. **Is he/she sensitive to food textures?**

6. **Associate Feeding Problems – estimate the frequency of the following:**
    a. **Vomiting:**

    b. **Teeth grinding:**

c. **Food allergies:**

d. **Coughing:**

e. **Gagging:**

f. **Diaphoresis (profuse perspiration)**

g. **Aspiration**

7. **Has he/she ever had a feeding tube?**

a. **Describe the date and details**

Part 3. Adaptive Behavior

1. **Current Feeding Skills:**

a. **Feeds self with spoon?**

b. **Feeds self with fork?**

c. **Uses knife?**

d. **Drinks from cup/glass?**

e. **Pours own drink?**

f. **Prepares own snack?**

2. **Other behavioral or developmental problems:**
   a. **Please list any speech delays, behavior problems, toileting problems**

Part 4. Motivation

Please provide the following:

Favorite foods:

Favorite recreational materials:

Favorite activities:

Anything additional you would like to add:

Appendix B: Survey of Participant Aides

Name of Client who participates in class:_____

Name of Aide:_____

1. This class is intended to teach the client how to construct salads by learning to cut and chop vegetables. How well do you expect him/her to do on a scale of 0 to 5? 0 means no participation and 5 means full participation.

0 1 2 3 4 5

2. This class is intended to help the client learn to enjoy eating fruits and vegetables in salad form. How well do you expect him/her to do on a scale of 0 to 5? 0 means refusal to eat and 5 means eating salad completely

0 1 2 3 4 5

3. How particular is the client regarding food on a scale of 0 to 5? O being refuses to eat all but a few, specific foods and 5 means eats everything put before him/her.

0 1 2 3 4 5

Below please indicate any food related or general behaviors that you feel will influence his/her participation in the class.

Thank you!

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